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Levelling Up: Computerised therapy for depression  
among adolescents alienated from  
mainstream education

Theresa Margaret Fleming

A thesis submitted in fulfillment of the requirements  
for the degree of Doctor of Philosophy in Psychiatry  
The University of Auckland  
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# Abstract

## Background

Adolescents in alternative schooling programmes for those alienated from mainstream education ('adolescents in alternative schooling') have high rates of depression and yet seldom receive treatment. Computerised Cognitive Behavioural Therapy (cCBT) is effective for depression among adults and has the potential to increase the availability of psychotherapy. There have been few adolescent specific cCBT programmes, little investigation of cCBT for adolescents, and no investigation of the potential of cCBT among adolescents in alternative schooling.

## Aims

To explore the acceptability, effectiveness and feasibility of cCBT for symptoms of depression among adolescents in alternative schooling.

## Methods

- 1) An adolescent specific cCBT programme for symptoms of depression was developed with a multidisciplinary team, and with youth and expert input.
- 2) Semi structured interviews and focus groups were held with 40 youth service providers who work closely with adolescents alienated, or at risk of being alienated, from mainstream schooling.
- 3) Focus groups were carried out with 39 adolescents (29 male; 19 Maori; 10 Pacific Island; 10 New Zealand European/other; all 13-16 years old) in alternative schooling.
- 4) A pragmatic randomised controlled trial of cCBT (SPARX) with students in alternative schooling. Participants (32 with symptoms of possible depression and 12 without symptoms; 30 male; 17 Maori; 14 Pacific Island; 13 New Zealand European/other; all 13-16 years old) were randomised to immediate or delayed cCBT. Effectiveness was tested for students with depressive symptoms at baseline.
- 5) Semi-structured interviews with 39 trial participants (30 with symptoms of possible depression; 24 male; 15 Maori; 12 Pacific Island; 12 New Zealand European/other), a staff member at each participating site and 10 parents or caregivers of adolescents who had participated in the trial.

## **Results**

A cCBT programme 'SPARX', utilising a bi-centric frame of reference, a game like interface and incorporating common elements of therapy and CBT content, was developed. Youth service providers were interested in utilising cCBT; many would wish to do so with all the young people in their programmes. Some were concerned that cCBT might displace human support. Adolescents considered that hurting oneself or others were common ways of responding to depression and that asking for help was very unlikely. They were interested in cCBT, especially if this could be provided without the need for them to be identified as having a problem. Among the 30 students with symptoms of depression who began treatment as randomised and provided 5 week data, significant differences were found between cCBT and wait groups on the Children's Depression Rating Scale-Revised (primary outcome measure) (baseline to 5 week mean change -14.7 vs. -1.1,  $p < .001$ ), remission (78% vs. 36%,  $p = 0.047$ ) and the Reynolds Adolescent Depression Scale 2<sup>nd</sup> edition (-4.6 vs. +3.2  $p = 0.05$ ), but not on other psychological functioning scales. Gains were maintained at 5 week follow up. Participants with and without depressive symptoms considered cCBT helpful, often because it helped with anger, fighting or relationships. Most considered that cCBT would increase help-seeking and thought it should be offered to all students. Parents and providers were satisfied with SPARX, although providers considered the support from the researcher important in implementation.

## **Conclusion**

Computerised CBT holds promise for use with adolescents in alternative schooling.

## Acknowledgements

I would like to thank the young people who participated in this research. They were open, enthusiastic and had truly valuable insights on good ways to support the mental health of other young people. It was a pleasure to work with them. Seeing the dedication and skills of youth workers and alternative schooling providers over the years was part of what inspired me to do this research; I am humbled by their openness and the welcomes that they gave when I came along to ask about a new way of doing things. Their support was invaluable. I would like to thank the families who supported their young people to participate in the research and those who provided feedback themselves.

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# Table of contents

<b>ABSTRACT</b>	<b>III</b>
<b>ACKNOWLEDGEMENTS</b>	<b>V</b>
<b>TABLE OF CONTENTS</b>	<b>VII</b>
<b>LIST OF TABLES</b>	<b>X</b>
<b>LIST OF FIGURES</b>	<b>XI</b>
<b>TERMS AND ABBREVIATIONS</b>	<b>XII</b>
<b>CHAPTER 1: INTRODUCTION</b>	<b>13</b>
THEORETICAL APPROACH	14
RESEARCH QUESTIONS	15
OVERVIEW OF THESIS	15
<b>CHAPTER 2: ADOLESCENTS IN ALTERNATIVE SCHOOLING</b>	<b>17</b>
PART 1: MAINSTREAM AND ALTERNATIVE SCHOOLING	17
<i>The significance of education</i>	17
<i>Registered schools and alternative schooling in New Zealand</i>	18
<i>Defining ‘adolescents in alternative schooling’</i>	21
PART 2: ADOLESCENCE	24
<i>The developmental context</i>	26
<i>Implications</i>	27
PART 3: ADOLESCENTS IN ALTERNATIVE SCHOOLING	28
<i>Demographics and family contexts</i>	28
<i>Becoming alienated from schooling</i>	28
<i>Educational achievement</i>	29
<i>Current health and wellbeing</i>	29
<i>Health service utilisation</i>	30
<i>The impact of being in alternative schooling</i>	32
WHY FOCUS ON ADOLESCENTS IN ALTERNATIVE SCHOOLING?	33
<b>CHAPTER 3: DEPRESSION AMONG ADOLESCENTS IN ALTERNATIVE SCHOOLING</b>	<b>35</b>
PART 1: WHAT IS DEPRESSION?	35
<i>Conceptualising depression</i>	35
<i>DSM and ICD definitions of depression</i>	36
<i>Aetiology of depression</i>	37
<i>Measuring depression</i>	40
<i>Differences among groups of people</i>	41
PART 2: WHY IS DEPRESSION IMPORTANT AMONG ADOLESCENTS IN ALTERNATIVE SCHOOLING?	43
<i>Rates of depression</i>	43
<i>The impact of depression</i>	44
<i>Why prioritise depression?</i>	46
PART 3: TREATMENT AND PREVENTION OF DEPRESSION AMONG ADOLESCENTS	47
<i>Treatment</i>	47
<i>Prevention</i>	49
<i>Barriers to treatment</i>	50
<i>Computerised CBT</i>	51
<i>Computerised CBT for adolescent depression</i>	54



<i>Interventions for depression among adolescents in alternative schooling</i> -----	55
<i>Computerised CBT: an opportunity for adolescents in alternative schooling?</i> -----	56
PART 4: THE DEVELOPMENT OF 'SPARX' CCBT PROGRAMME FOR ADOLESCENTS-----	59
<i>The beginnings and my own role</i> -----	59
<i>Programme Aims</i> -----	60
<i>Literacy and Computer Literacy</i> -----	60
<i>Putting therapy onto a computer programme</i> -----	61
<i>Therapeutic relationship and common elements of therapy</i> -----	62
<i>Learning and behaviour change</i> -----	62
<b>CHAPTER 4: METHODOLOGY</b> -----	<b>67</b>
RATIONALE-----	67
<i>A pragmatic mixed methods approach</i> -----	68
METHODOLOGY FOR THIS RESEARCH-----	70
<i>Focus Groups and Interviews</i> -----	72
<i>Analysis of focus group and interview data</i> -----	72
<i>A pragmatic trial</i> -----	73
<i>Integrating results</i> -----	74
SUMMARY-----	74
<b>CHAPTER 5: STUDY 1: YOUTH WORK SERVICE PROVIDERS' ATTITUDES TOWARDS CCBT</b> -----	<b>76</b>
PREAMBLE-----	76
'YOUTH WORK SERVICE PROVIDERS' ATTITUDES TOWARDS COMPUTERISED CBT FOR ADOLESCENTS' (IN PRESS) <i>BEHAVIOURAL AND COGNITIVE PSYCHOTHERAPY</i> -----	77
<i>Abstract</i> -----	77
<i>Introduction</i> -----	77
<i>Methods</i> -----	79
<i>Results</i> -----	81
<i>Discussion</i> -----	88
<i>References</i> -----	92
<b>CHAPTER 6: STUDY 2: THE VIEWS OF ADOLESCENTS</b> -----	<b>96</b>
PREAMBLE-----	96
'IT'S MEAN!' THE VIEWS OF YOUNG PEOPLE ALIENATED FROM MAINSTREAM EDUCATION ON DEPRESSION, HELP SEEKING AND COMPUTERISED THERAPY.' (2012) <i>ADVANCES IN MENTAL HEALTH</i> -----	97
<i>Abstract</i> -----	97
<i>Introduction</i> -----	97
<i>Methods</i> -----	99
<i>Findings</i> -----	102
<i>Discussion</i> -----	106
<i>References</i> -----	109
<b>CHAPTER 7: STUDY 3: A PRAGMATIC RANDOMISED CONTROLLED TRIAL</b> -----	<b>113</b>
PREAMBLE-----	113
<i>Issues identified in Studies 1 &amp; 2 relevant for the design of the trial.</i> -----	113
'A PRAGMATIC RANDOMISED CONTROLLED TRIAL OF COMPUTERISED CBT (SPARX) FOR SYMPTOMS OF DEPRESSION AMONG ADOLESCENTS EXCLUDED FROM MAINSTREAM EDUCATION.' (2011) <i>BEHAVIOURAL AND COGNITIVE PSYCHOTHERAPY</i> -----	115
<i>Abstract</i> -----	115
<i>Introduction</i> -----	116
<i>Methods</i> -----	117
<i>Results</i> -----	120
<i>Discussion</i> -----	124

REFERENCES	127
AFTERWORD	131
<b>CHAPTER 8. STUDY 4: ADOLESCENT, PARENT AND PROVIDER FEEDBACK</b>	<b>133</b>
PREAMBLE	133
PART 1: 'CALMS YOU DOWN AND SMOOTHS THE WAY: EDUCATIONALLY ALIENATED ADOLESCENTS' VIEWS ON IN THE IMPACT AND UTILITY OF COMPUTERISED CBT (SPARX).' <i>IN REVIEW</i>	135
<i>Abstract</i>	135
<i>Introduction</i>	135
<i>Methods</i>	137
<i>Findings</i>	139
<i>Discussion</i>	146
<i>References</i>	148
PART 2: PARENT AND ALTERNATIVE SCHOOLING PROVIDERS FEEDBACK ON THE USE OF SPARX'	152
<i>Abstract</i>	152
<i>Introduction</i>	152
<i>Methods</i>	153
<i>Results</i>	154
<i>Discussion</i>	156
<i>References</i>	158
<b>CHAPTER 9: DISCUSSION</b>	<b>161</b>
ACCEPTABILITY, EFFECTIVENESS AND FEASIBILITY	162
<i>Acceptability</i>	163
<i>Effectiveness</i>	165
<i>Feasibility</i>	166
<i>Summary</i>	167
COMPARISON WITH OTHER INTERVENTIONS FOR DEPRESSION AMONG ADOLESCENTS IN ALTERNATIVE SCHOOLING	167
STRENGTHS AND LIMITATIONS	168
IMPLICATIONS AND QUESTIONS FOR FUTURE RESEARCH	170
<i>Clinical Implications</i>	170
<i>Implications for other groups</i>	170
CONCLUSION	174
<b>APPENDICES</b>	<b>175</b>
<b>APPENDIX A: TYPES OF REGISTERED SCHOOL IN NEW ZEALAND</b>	<b>176</b>
<b>APPENDIX B: SEARCH TERMS</b>	<b>177</b>
<b>APPENDIX C: INTERVIEWS AND FOCUS GROUPS, DESCRIPTION OF PROCEDURES</b>	<b>178</b>
<b>APPENDIX D: PSYCHOMETRIC RATING SCALES USED IN THE TRIAL</b>	<b>183</b>
<b>APPENDIX E: PARTICIPANT INFORMATION SHEETS AND CONSENT FORMS</b>	<b>184</b>
<b>REFERENCES</b>	<b>207</b>

# List of Tables

TABLE 1: MINISTRY OF EDUCATION FUNDED ALTERNATIVE PROVISION FOR STUDENTS ALIENATED FROM MAINSTREAM SCHOOLING .....	19
TABLE 2: GENDER AND ETHNICITY OF YOUNG PEOPLE IN ALTERNATIVE SCHOOLING IN NEW ZEALAND .....	31
TABLE 3: CONTEXTS AND HEALTH BEHAVIOURS OF NEW ZEALAND AE AND MAINSTREAM SCHOOL STUDENTS <sup>1</sup> .....	31
TABLE 4: INTERVENTIONS TO TREAT OR PREVENTION DEPRESSION AMONG ADOLESCENTS IN ALTERNATIVE SCHOOLING, 1995-2008 .....	57
TABLE 5: THERAPEUTIC ELEMENTS INCLUDED IN THE CCBT PROGRAMME .....	61
TABLE 6: PROGRAMME OUTLINE.....	65
TABLE 7: INTERVIEW GUIDE .....	80
TABLE 8: PARTICIPANT DEMOGRAPHICS.....	100
TABLE 9: QUESTIONS USED TO GUIDE FOCUS GROUP DISCUSSION.....	101
TABLE 10: NUMBERS OF PARTICIPANTS WHO WOULD WANT TO USE A PROGRAMME SUCH AS SPARX IF THEY WERE FEELING DOWN ...	106
TABLE 11: PRIMARY AND SECONDARY OUTCOMES AT BASELINE AND MEAN CHANGES AT 5 WEEKS.....	123
TABLE 12: MAINTENANCE OF EFFECTS: MEAN SCORES ON PRIMARY AND SECONDARY OUTCOMES IMMEDIATELY POST INTERVENTION AND AT FOLLOW UP FOR PARTICIPANTS WHO RECEIVED SPARX IMMEDIATELY .....	123
TABLE 13: THEMES FROM INTERVEIWS .....	142
TABLE 14: QUESTIONNAIRE RESPONSES .....	145
TABLE 15: PARENT FEEDBACK.....	154
TABLE 16: PROVIDER INTERVIEWS AND FEEDBACK.....	155
TABLE 17: THE CONTRIBUTION OF STUDIES 1, 2, 3 & 4 TO THE CONSIDERATION OF ACCEPTABILITY, EFFECTIVENESS AND FESIBILITY CRITERIA.....	163

# List of Figures

FIGURE 1: SCREEN SHOTS OF THE SPARX CCBT PROGRAMME .....	66
FIGURE 2: OVERVIEW OF THE RESEARCH PROGRAMME TO INVESTIGATE THE USEFULNESS OF CCBT OF SYMPTOMS OF DEPRESSION AMONG ADOLESCENTS IN ALTERNATIVE SCHOOLS .....	71
FIGURE 3: FLOW CHART OF PARTICIPANTS IN THE TRIAL .....	121

## Terms and Abbreviations

AE	Alternative Education
CBT	Cognitive Behavioural Therapy
cCBT	Computerised Cognitive Behavioural Therapy
CDRS-R	Children's Depression Rating Scale-Revised
GP	General Practitioner
PRU	Pupil Referral Unit
RADS	Reynolds Adolescent Depression Scale
RADS-2	Reynolds Adolescent Depression Scale, 2 <sup>nd</sup> Edition
RCT	Randomised Controlled Trial

### Important note regarding terms

The population of interest for this thesis is adolescents in alternative schooling programmes for young people alienated from mainstream education. This is an awkward phrase. For convenience and flow I have shortened this to adolescents in 'alternative schooling' where this can be done while retaining clarity. Although 'alternative schooling' could potentially include non-mainstream choices such as Steiner schools, the focus in this thesis is on schooling programmes specifically for adolescents who have been alienated or excluded from school and who are considered to have significant difficulties in ordinary state schooling environments. In New Zealand these programmes include Alternative Education units (Ministry of Education, 2011a).

'Alternative education' can be used to refer to any alternative schooling programme for alienated students or specifically to Alternative Education (AE) established under very specific Ministry of Education criteria. To avoid confusion here I have used capitals (Alternative Education) to refer to the units established under specific Ministry of Education criteria.

## Chapter 1: INTRODUCTION

This research concerns the use of computerised cognitive behavioural therapy (cCBT) for symptoms of depression among adolescents who are in alternative schooling programmes for those alienated from mainstream education (hereafter referred to as ‘adolescents in alternative schooling’). In this introduction I will outline why adolescents in alternative schooling are an important group, why depression is significant for them and why cCBT is worthy of exploration.

Education is a powerful predictor of health and wellbeing (Freudenberg & Ruglis, 2007). Compared to those who gain formal school qualifications, young people who leave school early have lower rates of participation in tertiary training, lower income, higher rates of health difficulties and shorter life expectancy (D. M. Fergusson, Swain-Campbell, & Horwood, 2002; Freudenberg & Ruglis, 2007; Ou, 2008; Tyler & Lofstrom, 2009). In New Zealand most young people now stay in school until they are 17 or 18 years of age (Education Counts, 2011c) and over 90% leave with some formal qualifications (Ministry of Education, 2009a). However, some adolescents are alienated from education while in their compulsory schooling years. Alternative schooling programmes such as Alternative Education (AE) and Activity Centres have been established in many countries for students who are alienated or excluded from mainstream schooling and who are considered to need alternative approaches (De Jong & Griffiths, 2006; Education Review Office, 2011; Gutherson, Davies, & Daszkiewicz, 2011; Lehr, Tan, & Ysseldyke, 2009). Adolescents in alternative schooling have high rates of social and health difficulties, including mental health difficulties such as depression (Berridge, Brodie, Pitts, Porteous, & Tarling, 2001; Clark et al., 2010; Denny, Clark, Fleming, & Wall, 2004; Foley & Pang, 2006; Grunbaum, Lowry, & Kann, 2001; Howell, 2011; Kim & Taylor, 2008; Smith et al., 2007; Van Acker, 2007).

Depression is distressing and is associated with increased risk of suicide, future episodes of depression, school failure, substance abuse, self-harm and reduced earning potential (Birmaher et al., 1996; Rao & Chen, 2009). Ongoing depression, with its attendant hopelessness and lack of motivation, can act as a barrier for addressing concurrent difficulties. There are evidence based therapies for depression (David-Ferdon & Kaslow, 2008; Weisz, McCarty, & Valeri, 2006); however, the majority of young people with depressive symptoms do not receive mental health treatments (Zachrisson, Rödje, & Mykletun, 2006) and adolescents in AE report more difficulties accessing help than other students do (Clark et al., 2011).

Computerised CBT has developed as a way of increasing access to treatment (Kaltenthaler & Cavanagh, 2010) and has been found to be effective for adults with depression (Andrews, Cuijpers, Craske, McEvoy, & Titov, 2010; Richards & Richardson, 2012). There has been less investigation of cCBT for

adolescents with depression; however, recent, mainly small, trials suggest that this is promising (Attwood, Meadows, Stallard, & Richardson, 2011; Calear & Christensen, 2010; Merry et al., 2012; Richardson, Stallard, & Velleman, 2010; Stallard, Richardson, Velleman, & Attwood, 2011). There is no research regarding the use of cCBT with young people who are in alternative schooling or are alienated from mainstream education. I developed this research to investigate whether cCBT might be an acceptable, feasible and potentially effective intervention for adolescents with symptoms of depression who were in alternative schooling. I was interested in this question because of my previous clinical work and research. In the 1990s I had observed how marginalised young people appear to become if they leave school while under the legal school leaving age. Later I was involved in the establishment of health services for young people in AE. It was striking how many AE students formed close relationships with tutors and appeared to engage in learning and make positive life changes while in AE. However many of their efforts appeared to be thwarted by ongoing challenges such as depression. Obtaining support from mental health services did not seem to be acceptable or engaging for students. I went on to work in adolescent mental health services, where I observed that providing support for AE students was also challenging from the perspective of mental health services. It seemed that these were adolescents with particularly high needs and yet existing models of care failed to assist them. Through these experiences, and research in which I was involved, I came to consider that other approaches, facilitated via persons to whom young people were close, were required. This research investigates whether cCBT offered through alternative schooling programmes might offer one way forward.

## **Theoretical approach**

I have utilised a post positivist paradigm (Morris, 2006; Quinn Patton, 2002); experimental methods have been utilised but with a greater emphasis on the context of findings and the importance of multiple sources than is typically the case in traditional objectivist methods. The research questions and methods are influenced by social work ethics (Aotearoa New Zealand Association of Social Workers, 2008; The International Federation of Social Workers, 2012) and youth health principles (Bennett & Tonkin, 2003; Kidz First Centre for Youth Health & Youth Health Expert Working Group, 2006; Society for Adolescent Medicine, 2009). Thus I have attempted to carry out research that is informed by and informative of practice, includes an emphasis on empowerment, promotes social inclusion and the reduction of inequalities, includes the perspectives of young people and other stakeholders, and supports the development of effective, appealing services for young people.

## Research questions

This research was designed to investigate whether cCBT offered through alternative schools might be useful for reducing the symptoms of depression among these schools' students. As there was a lack of cCBT programmes for depression among adolescents, I contributed to the development of an adolescent specific cCBT programme. Alongside and following this, I explored the acceptability and feasibility of implementing cCBT in alternative schooling and tested the likely effectiveness of cCBT for symptoms of depression among adolescents in alternative schooling via four related studies:

1. An investigation of the views and opinions of youth work service providers (including alternative schooling providers) that might impact on the potential utilisation of cCBT through their services.
2. An investigation of the perspectives and preferences of adolescents in alternative schooling regarding depression, treatment for depression and computerised therapy.
3. A pragmatic trial investigating whether cCBT is likely to be effective for symptoms of depression among adolescents in alternative schooling.
4. An investigation of the views of trial participants and parents and alternative schooling providers regarding the experience and impact of cCBT and how it might best be used with other young people.

## Overview of thesis

This thesis is presented in accordance with the 2011 University of Auckland PhD thesis regulations for PhD with publication.

The thesis consists of 9 chapters. The current chapter provides an introduction to the thesis and the approach taken. Chapter 2 describes adolescents in alternative schooling. Chapter 3 outlines depression, why it is a significant issue and what can be done about it. It describes available cCBT programmes and outlines the development of a new, adolescent specific cCBT programme, 'SPARX'. Chapter 4 describes the overall methodology for the research.

Chapters 5 to 8 present the four studies which were undertaken in this research. Each of these chapters consists of a preamble or introductory section followed by a research article which reports that study. Chapter 5 reports the study of youth work service providers' views, chapter 6 reports the study regarding adolescents' perspectives, and chapter 7 presents the trial. Chapter 8 consists of two parts: firstly, the views of adolescents who had participated in the trial of cCBT and, secondly, parent and alternative schooling providers' feedback.

Finally, in chapter 9, implications of these findings are considered and conclusions are made.



Research articles which have been published are included exactly as published, apart from being formatted consistently with the remainder of the thesis (rather than included in the published format); pages, tables and figures in these articles are renumbered so that numbering is continuous throughout the thesis. One correction to article included in chapter 7 has been made: that is where the term 'efficacy' was used in error instead of 'effectiveness', this has been corrected. I am the lead author on all of the publications; I planned and carried out the studies, wrote the text for each article, reviewed it with co-authors and wrote the final article.

In accordance with the University of Auckland PhD thesis regulations for PhD with publication, introductory and closing chapters provide context around the publications.

## **Chapter 2: ADOLESCENTS IN ALTERNATIVE SCHOOLING**

In this chapter I describe 'adolescents in alternative schooling' and discuss why they are an important group of young people on which to focus. The chapter consists of three parts. In Part 1, 'Mainstream and Alternative schooling', I review why education is significant, describe mainstream and alternative schooling provision in New Zealand, and specify who 'adolescents in alternative schooling' are. In Part 2, 'Adolescence', I review contemporary perspectives of development in adolescence. I focus on the 13-16 years age range, as this is the age range of students in alternative schooling. In Part 3, 'Adolescents in Alternative Schooling', I review what is known about the health and development of young people in alternative schooling. I conclude with a summary of why it is important to focus on adolescents in alternative schooling.

### **Part 1: Mainstream and alternative schooling**

#### **The significance of education**

Education is seen as critical for the development of economies and of individuals. It is a powerful predictor of health status. Education of children is considered both a right and an obligation in most of the world.

An educated workforce is widely described as necessary for the development of modern nations. Educated, skilled workers are thought to contribute to increased productivity and economic growth (Earle, 2010). Education also has social purposes including the development of values consistent with workforce participation (Ministry of Education, 2009b), reducing social exclusion and social destabilisation (Sparkes, 1999), and reducing welfare costs and crime rates (Tyler & Lofstrom, 2009).

On an individual level, school retention and educational achievement are highly correlated with adult employment and income measures (Sparkes, 1999). Early school leavers and those without any school qualifications generally have fewer job opportunities, higher rates of unemployment and lower income than those who leave with qualifications (Freudenberg & Ruglis, 2007; Sparkes, 1999; Tyler & Lofstrom, 2009). Basic literacy and numeracy are particularly important for participation in work and day to day functioning in many aspects of contemporary society (Ministry of Education, 2002; Sparkes, 1999).

Education appears to exert a powerful influence on health status. Higher education predicts longer life expectancy, lower rates of health risk behaviours (Freudenberg & Ruglis, 2007; Tyler & Lofstrom, 2009), higher health literacy (Ministry of Health, 2010), and improved health among one's children (Ou, 2008).

These effects may be linked to higher income, greater experiences of personal control, choice, social support and prestige, or increased utilisation of information and resources. All of these are linked to both health and to education (Freudenberg & Ruglis, 2007).

School attendance for children in New Zealand has long been considered both an obligation and a right. Schooling has been compulsory since 1877. Since 1993, young people have been required to be enrolled in a registered school from their 6<sup>th</sup> until their 16<sup>th</sup> birthday, unless they are a foreign student or have a legal exemption (Education Act, 1989). In recent years there have been proposals to further extend these requirements (New Zealand Press Association, 2008). In 1959 the United Nations (UN General Assembly, 1959) proclaimed education to be a right of every child in order to both “develop his abilities” and to “become a useful member of society” (UN General Assembly, 1959, Article 7). Within New Zealand, under the Education Act 1989, children have the right to primary and secondary school education from age 5 until the end of the calendar year following their 19th birthday (or, in the case of disabled students, their 21st birthday). Students who have special educational needs have the same rights to enroll and receive education at state schools as those who do not.

Thus meeting the educational needs of young people in New Zealand is important for economic, social and personal development. Access to quality, effective, appropriate education is the right of all young people.

## **Registered schools and alternative schooling in New Zealand**

### ***Registered schools***

In New Zealand registered schools include state schools, schools with special character, state integrated schools and private schools, as listed in Appendix A. All are charged with teaching the New Zealand curriculum or, in the case of private schools, a curriculum of at least the same quality. All must meet the National Education Goals, which include the development of the full potential of all individuals, equality of educational opportunity, the removal of barriers to achievement, programmes to meet individual needs and increased participation and success by Maori (Ministry of Education, 2009b). Schools must also follow National Administration Guidelines, which include the requirement to provide all students with opportunities to achieve and to identify and meet the needs of students who are not achieving or have special needs (Ministry of Education, 2010).

Schools appear to engage most but not all students. Over 80% of young people in New Zealand are enrolled to their 17<sup>th</sup> birthday and beyond (Education Counts, 2011c) and over 90% leave school with some formal qualification (Ministry of Education, 2009a). However, despite inclusive educational goals

and the interventions that are offered by many schools, there are young people who are not well served by, or engaged with, schools. Also, schools have the right to exclude or expel students and to refuse to enroll excluded or expelled students in certain circumstances ("Education Act 1989," 1989).

### ***Alternative schooling***

For students who are excluded or alienated from schools and are considered difficult to teach in usual school environments there are other programmes which the Ministry of Education describes as 'alternative provision' (Ministry of Education, 2011a). These are also referred to as 'alternative schooling' or 'alternative education'. Ministry of Education funded alternative provision for students alienated from mainstream schools consists of Alternative Education (AE), Activity Centres, and, in some cases, The Correspondence School (Ministry of Education, 2011a). The entry criteria for these are listed in Table 1.

**Table 1: Ministry of Education funded alternative provision for students alienated from mainstream schooling**

<b>Model</b>	<b>Entry Criteria</b>
Alternative Education (AE) <sup>1</sup>	<p>Education programmes for young people aged between 13 ½- 16 who are alienated from the education system and who are either unwilling to attend a regular school or whom schools are unwilling to enroll in a mainstream setting.</p> <p>The target group is young people who fit one or more of the following criteria:</p> <ul style="list-style-type: none"> <li>- have been out of school for two terms or more</li> <li>- have a history of multiple exclusions</li> <li>- were referred to The Correspondence School as a last resort and have dropped out</li> <li>- have been absent for at least half of the last 20 weeks for reasons other than illness, and the absence has meant that they are unable to maintain a mainstream programme</li> <li>- have been suspended or excluded and are at risk of further suspensions/exclusions.</li> </ul> <p>AEs may include up to 20% of students who do not meet these criteria.</p>
Activity Centres	Units for year 9-13 students at risk of not achieving in mainstream education; specific criteria are set by schools (Ministry of Education, 2009a). Most students are referred for behaviour that impedes their learning and that of others (Education Review Office, 2009).
The Correspondence School <sup>1</sup>	One of the functions of the Correspondence School is to provide schooling for students who are unwilling to go to local schools or whom local schools are unwilling to enroll. These students must have supervision arrangements and must be approved by the Ministry of Education.

<sup>1</sup> Source: Ministry of Education (2011a)

In 2010 there were 1820 fulltime funded student places in Alternative Education (AE) with about 3500 students participating per year (Education Review Office, 2011) (students are enrolled fulltime, but many attend for only part of the year). This is approximately 1% of 13-15 year olds in NZ schools. In 2009 AE was provided by 106 consortia, with over 200 different providers (Ministry of Education, 2009a). While students are at AE they are enrolled in a registered school but attend an alternative learning space, often away from the school site, in small groups (usually up to 20). Enrolling schools are expected to take an active interest in students attending AE; however, the Education Review Office (2011) reported that most schools do not actively monitor the progress of these students.

Resources in AE may be quite different from those available in ordinary high school settings. AE teaching is typically provided by tutors rather than qualified teachers, although tutors must have access to qualified teachers. Many AEs operate out of church or community buildings. Many do not have access to sports facilities or specialist learning environments such as workshops, libraries, or computer facilities. Most do not have routine access to guidance counsellors, careers advisors or onsite health services. Despite their legal right to education until the end of the year in which they turn 19 (Education Act, 1989), students are not funded to attend AE beyond 16 years of age.

AE centres are charged with re-integrating students into education and improving educational outcomes. However, few AE students return to school (Ministry of Education, 2009a) and student achievement in AE is very different from that in mainstream schooling. For example, of students enrolled in AE in 2007, only 26% continued their education elsewhere the following year (Ministry of Education, 2008). In terms of formal qualifications, 90.4% of students followed up from AE for up to four years had little or no formal attainment (Ministry of Education, 2009a). In contrast, in 2007 4.7% of students left mainstream education with little or no formal attainment (Ministry of Education, 2009a).

Activity Centres provide alternative schooling for a smaller number of students. In 2009 a total of 205 students were enrolled in Activity Centres nationwide (Education Review Office, 2009). The entry criteria for Activity Centres are set with referring schools and are not tightly specified by the Ministry of Education, in contrast with the entry criteria for AE. Most focus on Year 9 and 10 students with a goal of re-integrating them into school (Education Review Office, 2009). There are only 14 Activity Centres nationwide; these are not necessarily located in areas with the highest levels of need for alternative provision (Ministry of Education, 2009a).

The Correspondence School is the largest school in New Zealand, with 24,000 students a year studying full or part-time (Te Aho o Te Kura Pounamu, 2012). Some of its pupils are enrolled as 'at risk' students. Students receive instruction by correspondence and are expected to be motivated and organised

enough to work through this at home. The Correspondence School has responsibility for the safety and achievement of these students, although they have limited capacity to ensure this (Ministry of Education, 2009a). Data regarding the numbers and progress of enrolled at risk students are not readily accessible. The Correspondence School also provides education for students who find it difficult to get to school for various reasons, such as living in an isolated area.

Of these options, AE in particular is seen as 'last resort' education for those who are most difficult to engage in schooling. Students may be referred to AE if their needs are not met in Activity Centres or in The Correspondence School (Education Review Office, 2011).

### ***Young people who are not in registered schools or alternative schooling***

There are New Zealanders of compulsory schooling age who are not enrolled in school or alternative schooling. These include young people who are granted home schooling exemptions or early leaving exemptions (Education Counts, 2011a) and young people who are not enrolled and do not have an exemption, i.e. 'non enrolled truants' (Education Counts, 2011b; T. Fleming, 2006).

### **Defining 'adolescents in alternative schooling'**

There is no single definition for 'adolescents in alternative schooling.' For the purposes of this research I have utilised an operational definition which is consistent with Ministry of Education descriptions of 'alienated students' (Ministry of Education, 2009a, 2011a; O'Brien, Thesing, & Herbert, 2001; Te Kete Ipurangi, 2008, July) and is compatible with criteria used for comparable groups in other jurisdictions (Gutherson, et al., 2011; Howell, 2011; Kim & Taylor, 2008; KPMG, 2009; Smith, et al., 2007). That is adolescents who:

- are alienated, withdrawn or excluded from mainstream education, and
- are considered difficult to re-engage in schools because of the school's concerns and/or the young person's behaviour, and
- have enrolled in educational programmes especially for adolescents who are alienated from mainstream education.

This includes young people in Alternative Education, Activity Centres and other programmes which are explicitly for adolescents who are alienated from mainstream education. In some publications these young people are described as 'at risk' (Foley & Pang, 2006; Smith, et al., 2007), 'disruptive' (Foley & Pang, 2006), 'disengaged' (Smith, et al., 2007) or 'vulnerable' students (KPMG, 2009). They are also referred to as students who 'experience significant behavioural issues which may disrupt their own or other students learning' (Howell, 2011; KPMG, 2009), who display 'problem behaviour' (Grunbaum et

al., 2000) or 'anti-social behaviour' (Van Acker, 2007) and as students 'whose needs are not met in regular, vocational or special education schools' (Gutherson, et al., 2011).

The rationale for focusing on this group of students is based on their particularly high needs, including unmet health needs, and the potential to support them to achieve better outcomes while they are in alternative schooling. This rationale is expanded in this chapter.

I have not included the following groups:

- Students in teen parent units. Teen parent units are considered 'registered schools' rather than 'alternative provision' in New Zealand (see Appendix 1) and students in teen parent units are likely to have different needs from adolescents who are alienated from mainstream schooling
- Young people who are enrolled in the correspondence school as 'at risk students'. The Correspondence School is not specifically for alienated students. Information about 'at risk students' in The Correspondence School is not accessible, the students are hard to locate and interventions to meet the needs of these students would require different strategies.
- Young people who are outside of any education while under the school leaving age. These young people are also hard to find, there is limited information about them, and interventions to meet the needs of these students would require different strategies.
- Young people in progressive or non-traditional schools which parents or children have chosen as a more desirable option than mainstream schooling.

I have focused on *adolescents* alienated from mainstream schooling. Most young people who are identified as alienated from education are adolescents. For example in New Zealand 98% of school suspensions and school exclusions are of young people aged over 10 years (Ministry of Education, 2011b). AE and Activity Centres are explicitly for adolescents (Education Review Office, 2009).

### ***International relevance***

Adolescents who are disengaged or alienated from mainstream education are of concern around the world (Gulchak & Lopes, 2007; Nagata, 2006). There are alternative schooling provisions for young people who are alienated from mainstream education and considered unable to attend mainstream school for behavioural reasons in many regions, including the United States of America (Grunbaum, et al., 2000), Canada (Smith, et al., 2007), England, Scotland and Wales (Gutherson, et al., 2011; Stevens, Phillips, Chamberlain, & Knibbs, 2005), other parts of Europe (O'Brien, et al., 2001), Australia (De Jong & Griffiths, 2006), and some countries in Asia including South Korea (Nagata, 2006). The age range and criteria for entry to alternative education provisions vary and in many contexts are not well defined (Foley & Pang, 2006; Gutherson, et al., 2011). Most of the literature regarding alternative schooling

comes from the United States or England with some from Victoria (Australia), New South Wales (Australia) and British Columbia (Canada); hence the criteria in those jurisdictions are outlined here.

In the USA the Department of Education defines alternative education schools as:

A public elementary/secondary school that addresses the needs of students which typically cannot be met in regular school and provides non-traditional education which is not categorised solely as regular education, special education, vocational education, gifted and talented or magnet school programmes

US Department of Education, 2002, p 55 cited in Lehr et al, p 19

Most US states have legislation that further define alternative schooling (Lehr, et al., 2009), and this generally specifies that these schools are for students who are disruptive or problematic, who meet one or more 'at risk' criteria, who have been expelled or suspended, who have been violent, chronically disruptive or have behavioural problems, or who are at risk of drop out or failure (Lehr, et al., 2009; Murrihy, 2010). There were approximately 10,900 public alternative schools and programmes for at risk students with a total of 612,900 students in 2000-2001 (Kim & Taylor, 2008). Since that time alternative provision has grown rapidly, with an estimated one million students nationwide in alternative schools/programmes just one year later (Lehr, et al., 2009). Over 90% of alternative programmes are for secondary level students (Lehr, et al., 2009). Many of these include adolescents over the age of 16. For example, in 1997 over 50% of students in Alternative High Schools participating in the Youth Risk Behaviour Survey were aged over 16 years (Grunbaum, et al., 2001).

In the UK there were 511 'Pupil Referral Units' (PRUs) with a total of approximately 16,000 pupils in 2010 (Howell, 2011). These are units charged with reintegrating disaffected and disruptive pupils into mainstream school or into alternatives, which include Alternative Education and other programmes mandated through Local Authorities. Both PRUs and Alternative Education Programmes are considered alternative provision. Pupil Referral Units can take alienated people from under the age of 5; most pupils (93% in 2010), however, are 11 to 15 years old (Howell, 2011).

Alternative Education Programmes in Victoria (Australia) cater for vulnerable students who have significant difficulties or behavioural issues which cause disruptions to the learning of others or themselves (KPMG, 2009). In New South Wales, Alternative Education Programmes are for students who have been unable, for social, cultural or other reasons, to participate effectively in formal education and where other educational options are not suitable (Board of Studies NSW, 2011). Similarly, in British Columbia (Canada), alternative education programmes are aimed at high risk youth who are struggling in mainstream schooling and may be unable to adjust to the requirements of regular schools (Smith, et al., 2007).



In sum, there are alternative schooling programmes for adolescents who are considered alienated from schooling, disruptive or at risk and whose needs are not well met in usual schooling environments in many parts of the world. Accordingly, the current research can both utilise and contribute to international research.

## **Part 2: Adolescence**

In examining the needs of adolescents in alternative schooling, it is important to consider the role of developmental processes. In this section I provide an outline of adolescent development, focusing on the 13-16 years age range, this being the age range of students in alternative schooling programmes for those alienated from mainstream education.

Adolescence as a distinct and extended developmental period is a relatively recent, relatively Western concept. Although there is no one definition of adolescence, it is generally considered to be the period between childhood and adulthood (United Nations Childrens Fund, 2011). This has been operationalised as the period from the onset of puberty to the attainment of adult roles (Breinbauer & Maddaleno, 2005; United Nations Childrens Fund, 2011). Puberty most often begins between ages 9 and 12, although some girls show signs of puberty as early as 7 years of age (Breinbauer & Maddaleno, 2005). The attainment of adult roles is an amorphous concept often occurring well into the 3<sup>rd</sup> decade of life and beyond. To provide simple guidelines various age definitions are used; for example, the World Health Organisation and the United Nations define adolescence as 10 to 19 years (United Nations Childrens Fund, 2011).

Through much of the 20<sup>th</sup> century psychological traditions considered adolescence a period of 'storm and stress' (Hall, 1904), where conflict and distress were normative. However, work by Rutter and others highlighted that most adolescents were relatively healthy and managed life transitions without serious difficulties (Rutter, Graham, Chadwick, & Yule, 1976).

Today adolescence is considered to be a period of maturation, development and change which is influenced by biology, environment and the interactions between these (Dahl, 2004; Forbes & Dahl, 2010; Steinberg, 2010). It is considered to present both continuities and discontinuities with childhood and adulthood characteristics. The speed and complexity of maturation, the differences in timing of maturation of particular systems and the context in which they occur open up both opportunities and vulnerabilities for young people (Andersen & Teicher, 2008; Dahl, 2004; Steinberg, 2004, 2010). While a full review is beyond the scope of this thesis, it is important to highlight some of the changes which are of particular relevance in this body of research.

Adolescents in alternative schooling programmes are generally aged 13-16 years. For most young people this will be early or mid adolescence (Breinbauer & Maddaleno, 2005; Steinberg, 2008). While there are many individual differences, almost all people in this age group will have begun puberty and many will be reaching reproductive maturity. This means that most will have begun the pubertal growth spurt and many will have reached, or almost reached, adult height and will have developed, or be developing, secondary sexual characteristics (Breinbauer & Maddaleno, 2005; Christie & Viner, 2005; Steinberg, 2008). Thus most of these students will be considerably taller and stronger than they were as children and many will look more like adults than children.

As well as these obvious changes, puberty is associated with changes in emotion, motivation and arousal (Dahl, 2004). These include increased emotional reactivity (which may be important in the development of depression) (Cicchetti & Toth, 1998) and increased sensitivity to social status (which may add to barriers to seeking help for depression). There are also increases in romantic interest and sexual motivation and increases in exploratory behaviour, including some aspects of sensation seeking and novelty seeking (Dahl, 2004; Forbes & Dahl, 2010).

Alongside these changes there are multiple changes in brain morphology, function and connectivity. For example, there are changes in grey matter and white matter density, implying a gradual reduction in plasticity of the brain from around age 11 and an increase in processing speed for functions that are regularly used (Steinberg, 2010). There is development within the pre-frontal lobes. These areas have significant roles in planning, decision making, emotional processing and response inhibition. The maturation of these functions continues well into adulthood (Dahl, 2004; S. Johnson, Blum, & Giedd, 2009). There are also changes in location and availability of neurotransmitters, including reduced availability of dopamine, which has impacts on reward systems and emotions and might be important in the development of depression (Romer, 2010; Steinberg, 2010). These periods of plasticity may heighten adolescents' vulnerability to depression in the presence of stress (Andersen & Teicher, 2008).

There are other developments in adolescence too. The highly influential developmental psychologist Eric Erickson describes issues of competence (achievement vs. inferiority) as critical coming into this age range (approx. 6-11 years) and issues of identity development (fidelity, identity vs. role confusion) as especially important from approximately 12 to 20 years (Douvan, 1997; Nelson & Nelson, 2010). Following Erickson, a trend that occurs from early to late adolescence has been described in which many aspects of identity and morality move from 'inherited' (i.e., following notions that are common in the young person's milieu), through a stage of experimentation (trying out different notions or being inconsistent), to, finally, the consolidation of a stable identity.

Habits and patterns of behaviour which are developed or maintained in adolescence appear to lay foundations for many adult behaviours (Breinbauer & Maddaleno, 2005; National Research Council &

Institute of Medicine, 2009). For example, levels of exercise and cigarette smoking in adolescence predict adult activity and smoking (Breinbauer & Maddaleno, 2005). Where unhealthy habits such as heavy drinking and violence are not developed in adolescence, they are seldom initiated in adulthood (National Research Council & Institute of Medicine, 2009).

There are many changes in social relationships during adolescence. These are related to both maturation and social contexts. In early adolescence there is often increased peer influence, an increase in the intensity of peer relationships and the development of a crowd or group to hang out with. In later adolescence the development of intimate relationships is particularly salient (Forbes & Dahl, 2010; Nelson & Nelson, 2010; Steinberg, 2008). Relationships with parents and caregivers may change, with decreased direct parental control and reduced time in the care of parents being normal in many cultural contexts.

All of these changes interact with aspects of the social environment. As young people develop, there are many changes in their social context, including changes in schooling (transitions to and beyond secondary school), in availability of employment, in rights and legal status and in how others react to them and what they are expected to do. These vary across cultural and historical contexts and are often related to chronological age rather than maturation.

Developmental changes do not all occur in synchrony (Christie & Viner, 2005). Emotions and drives increase relatively early in adolescence, while formal reasoning may be more linked to age and education and occur later; the integration of cognitive and emotional responses is among the last systems to mature (Dahl, 2004; Steinberg, 2010).

## **The developmental context**

Adolescent development takes place within complex, changing, interacting personal and social environments and over time. Bronfenbrenner's 'Ecological Systems Theory' (Bronfenbrenner, 1979, 1989) and later 'Bioecological Systems Theory' (Bronfenbrenner, 2005) provide useful conceptual frameworks for articulating this. In brief, these theories identify development as being shaped by multiple interactions which take place in immediate environments (including internal, family, school and peer environments). These are in turn affected by larger social systems, the interactions between systems, and the history and pattern of events.

Adolescent development is influenced by risk and protective factors which increase or decrease the chances of negative outcomes. These are probabilistic and not deterministic; that is, they increase or decrease the chances of particular outcomes, but seldom directly cause specific outcomes (Masten &

Obradović, 2006) and seldom exert a large effect on their own (D. M. Fergusson & Lynskey, 1996). The timing of exposure to issues and the interaction of these with other characteristics of the young person and their environment are critical. Thus what is most significant appears to be cumulative exposure to multiple issues over time, and salient exposures during sensitive periods with consequent cascades of response (Cicchetti & Toth, 1998; Masten & Obradović, 2006; Moilanen, Shaw, & Maxwell, 2010; Taylor & Green, 2001). For example, in the Christchurch longitudinal study young people in the most disadvantaged 5% of the sample were at over 100 times greater risk of becoming 'multiple problem teenagers' than the most advantaged 50% of the sample (David M. Fergusson, Horwood, & Lynskey, 1994). However, it is important to remember that human behaviour, contexts and choices are sufficiently complex that even when an individual appears to have multiple risks or protective factors, they do not necessarily demonstrate the expected outcomes (Werner, 1993).

## **Implications**

The apparent malleability of adolescence suggests that this is a particularly important time to intervene to improve health outcomes (Breinbauer & Maddaleno, 2005; Committee on Prevention of Mental Disorders and Substance Abuse Among Children, 2009; National Research Council & Institute of Medicine, 2009). Evidence that patterns and habits formed in adolescence lay foundations for adult behaviour support this assertion (Breinbauer & Maddaleno, 2005; National Research Council & Institute of Medicine, 2009).

The uniqueness and complexity of the adolescent period suggests that interventions aimed to support adolescents need to be specifically tailored for this stage of life (rather than being adult or child focused). The complexity of changes suggests that even within the period of adolescence, different approaches may be required for those in different stages.

Finally, the concentration of risk of poor health outcomes among adolescents exposed to multiple disadvantages suggests that an emphasis on vulnerable young people is appropriate.

## **Part 3: Adolescents in Alternative Schooling**

### **Demographics and family contexts**

Adolescents in alternative schooling in New Zealand are mostly male and mostly Maori or Pacific Island young people (Table 2). All or almost all are aged 13 to 16 years; for example, in 2007 all students in AE and Activity Centres were aged 13-16, with most being 14 or 15 years old (Ministry of Education, 2009a). Most live in areas with high socio-economic deprivation (Clark et al., 2010) and face considerable socio-economic challenges (Denny, Clark, Fleming, et al., 2004 and see Table 3). Males, indigenous and ethnic minority students, and those from low socio economic communities are also overrepresented in alternative schooling in other parts of the world (Grunbaum, et al., 2001; Howell, 2011; K. Johnson & Taliaferro, 2012; KPMG, 2009; Smith, et al., 2007).

AE students have described both positive connections with family members and significant challenges in family relationships (Denny, Clark, Fleming, et al., 2004; O'Brien, et al., 2001). In a New Zealand survey of 335 AE students, Clark et al (2010) found that 64% of AE students felt close to their parents most of the time. However, only 35% of AE students reported that they usually got enough time with their mother and 37% usually got enough time with their father (Clark et al 2010). Indicators from this survey and comparable data for students in mainstream education are included in Table 3.

### **Becoming alienated from schooling**

There is no one pathway to students becoming alienated from school (Archambault, Janosz, Fallu, & Pagani, 2009; Li & Lerner, 2011). Broadly speaking, however, becoming alienated from mainstream education appears to be on a continuum with other school disengagement behaviours such as leaving school without educational qualifications (Kearney, 2008). In a comprehensive review Rumberger and Lim (2008) identified predictive factors of leaving school without educational qualification ('school dropout' in the US literature) from 203 empirical studies. These included factors such as ethnic minority status, non-participation in pre-school, high mobility between schools, low academic achievement, arrests or problem behaviour, stressful family events, low access to resources.

The literature regarding young people alienated from mainstream education is permeated with descriptions of students who have faced multiple hardships for many years. These include poverty, frequent changes in living arrangements, exposure to violence and frequent changes of school. Many of these students may have displayed dysregulated, violent behaviour at school and have become disengaged from education, often as they transition into high school during early adolescence

(Brooking, Gardiner, & Calvert, 2009; Clark, et al., 2011; De Jong & Griffiths, 2006; Foley & Pang, 2006; Howell, 2011; Smith, et al., 2007; Tyler & Lofstrom, 2009; Van Acker, 2007).

## **Educational achievement**

There is little detailed information about the academic achievements of young people in alternative schooling, beyond data discussed earlier (page 20) regarding low rates of achievement of formal qualifications (Bruce & Ferguson, 2011). Documents allude to AE students having difficulties with literacy and numeracy and their learning being behind their peers in school (Brooking, et al., 2009; Education Review Office, 2011; Ministry of Education, 2009a; O'Brien, et al., 2001). However, only one detailed review of literacy among New Zealand AE students was identified (Bruce & Ferguson, 2011). In this small study, students' literacy averaged that expected for 12 year olds; however variation was wide (Bruce and Ferguson, 2011).

## **Current health and wellbeing**

Surveys have identified high levels of health difficulties and risk behaviours among adolescents in alternative schooling compared to their in-school peers. In New Zealand the Adolescent Health Research Group carried out surveys of 268 and 335 AE students in 2001 (Denny, Clark, & Watson, 2004; Utter, 2002) and 2009 (Clark, et al., 2011; Clark, et al., 2010), respectively. A brief overview of findings from the 2009 survey is included here (Table 3). The same research group carried out a similar survey of secondary schools pupils in 2007. Available comparisons, adjusted to match the demographics of the AE sample are included (Table 3). As this table illustrates, rates of being in trouble with the police, being in serious fights, attempting suicide, smoking cigarettes, using marijuana and being sexually active are several times higher in AE students compared to high school students. Rates of depressive symptoms are also high among AE students, particularly among girls (more on this in chapter 3). Despite these challenges most AE students consider themselves to be healthy (Table 3).

Multiple risks in terms of social environments, mental health and health risk behaviours have also been reported in surveys of young people in alternative schooling in the US (Grunbaum, et al., 2000; Grunbaum, et al., 2001; K. Johnson & Taliaferro, 2012; Murrihy, 2010), Canada (Smith, et al., 2007), Australia (De Jong & Griffiths, 2006; KPMG, 2009) and the UK (Howell, 2011; Stevens, et al., 2005). Denny, Clark and Watson (2003) compared findings from the New Zealand and US AE surveys. They reported rates of disadvantage and difficulties to be similar.

## **Health service utilisation**

Although AE students generally consider themselves healthy (Table 3), 50% report that they have had difficulty accessing health care (Clark, et al., 2011; Clark, et al., 2010), and more AE students than school students report having been unable to access health care when they needed it (Clark, et al., 2010; Utter, 2002). Reasons for not being able to access health care that were most commonly endorsed in the 2009 New Zealand AE adolescent health survey were not knowing how to get an appointment (33%), 'couldn't be bothered' (32%) or 'didn't want to make a fuss' (30%) (Clark, et al., 2010). Other potential barriers to health care such as a lack of personal relationship with the provider, not considering that services might be able to help or not expecting to feel healthy have not been explored among young people in alternative schooling, although such issues have been identified as important in other research (T. Fleming, King, & Tregonning, 2008; Rickwood, Deane, Wilson, & Ciarrochi, 2005).

**Table 2: Gender and ethnicity of young people in Alternative Schooling in New Zealand**

Population	Source	Male	Maori (%)	Pacific Island (%)	New Zealand European/Pakeha (%)	Other (%)
Students in alternative provision (AE and Activity Centres)	Ministry of Education (2009a)	66%	61	11	26	2
Students in AE	Education Review Office (2011)	2/3	63	9	25	-
Students in Activity Centres	Education Review Office (2009)	67%	58	14	27	-

**Table 3: Contexts and Health Behaviours of New Zealand AE and mainstream school students<sup>1</sup>**

	Males in AE (%)	Females in AE (%)	Males in secondary schools <sup>2</sup> (%)	Females in secondary schools <sup>2</sup> (%)
Moved home 2 or more times in the previous year	34	47	13	15
Neither parent is in paid work	7	14	2	2
Parents worry about not having enough money for food: sometimes, often or always	40	47	16	21
Parents warm and loving most of the time	59	65	75	73
People at AE/school care some or a lot about them	95	91	91	91
Feel part of AE/school	93	89	89	90
Have been in trouble with the police in the previous 12 months	72	64	11	7
Ever been touched in a sexual way or made to do sexual things not wanted	11	41	5	20
Significant depressive symptoms (over the cut off on Reynolds Adolescent Depression Scale)	8	32	6	16
Attempted suicide in the previous year <sup>3</sup>	11	34	3	9
Been in a serious fight in the last year	71	65	24	13
Smoke cigarettes weekly or more	63	80	5	9
Binge drinking in the previous 4 weeks	86	96	50	55
Marijuana use weekly or more	59	48	5	4
Currently sexually active	75	74	22	15
Regards health as excellent, very good or good	88	73	93	90
Unable to see a doctor or nurse when needed in the previous 12 months	25	36	13	19

<sup>1</sup> Data were gathered in the New Zealand 2009 AE Adolescent Health Survey (Clark 2010) and the 2007 New Zealand School Adolescent Health Survey (Adolescent Health Research Group, 2008b). <sup>2</sup> School data are adjusted for age, gender, ethnicity and New Zealand Deprivation Index level to match the AE sample. With the exception of marked items (<sup>3</sup>), AE data and adjusted school data are currently unpublished (manuscript in preparation), and were generously shared by Dr Terryann Clark, Jodi Smith, and The Adolescent Health Research Group, University of Auckland. <sup>3</sup> Data published in Clark et al, 2010.



Partnerships with mental health services and other providers of pastoral care have been identified as important for alternative schools (De Jong & Griffiths, 2006; Gutherson, et al., 2011; Howell, 2011), but such partnerships are often lacking or are not well integrated with the schools (T. Fleming, 2007; Howell, 2011). Unlike many New Zealand high schools, most AEs do not have fulltime guidance counsellors or nurses on site.

Tutors and other staff in alternative schools may be aware of students' unmet health needs and some facilitate access to health care for students (Clark et al., 2011). However, barriers such as costs, transport, lack of knowledge regarding appropriate services and lack of services which are appropriate for AE students have been reported by staff in alternative schools (Clark et al., 2010, 2011). To date there has been little research investigating the role of alternative schooling providers in supporting the health needs of their students, despite suggestions that youth workers or others who are close to 'marginalised' young people might be particularly important in facilitating their access to services (Rickwood, et al., 2005).

In summary, although adolescents in alternative schooling have high health needs, they do not have good access to health care. In fact they appear to have more difficulty accessing services than their healthier peers in school do.

## **The impact of being in alternative schooling**

The impact of being in alternative schooling is difficult to predict. Few outcomes data are available (KPMG, 2009; Ministry of Education, 2009a), it is challenging to follow up the students once they have left alternative schooling (Pirrie & Macleod, 2009) and alternative schooling programmes vary significantly (Education Review Office, 2009, 2011; KPMG, 2009). However, there are frequently described experiences which might impact on students' development.

For many students a time lag of months or more occurs between leaving school and enrolling in alternative schooling (Berridge, et al., 2001; O'Brien, et al., 2001). Berridge and others (2001) have described this as a boring and frustrating or depressing period which involves a lack of structure, little contact with pro-social peers and a gradual loosening of young people's connections to conventional moral codes and mainstream institutions.

Clustering alienated students together in alternative schools might disrupt their attachments to general education settings and to the formal and informal opportunities provided therein (Van Acker, 2007). Clustering 'at risk' young people risks negative labelling of students and the creation of negative expectations (De Jong & Griffiths, 2006). Segregation also reduces peer diversity, which in this context

is likely to mean that high levels of risk behaviours are normal. This can lead to increases in antisocial behaviour and risk taking (De Jong & Griffiths, 2005, 2006; Van Acker, 2007).

Most young people in AE do not return to mainstream education or gain qualifications (Ministry of Education, 2009a). This does vary by educational provider (Education Review Office, 2009, 2011; KPMG, 2009); however, limited academic outcomes from AE are reported in New Zealand and elsewhere (Kim & Taylor, 2008; KPMG, 2009).

On a more positive note, many students describe feeling close to teachers and students and feeling cared for and more hopeful once they are in AE (Berridge, et al., 2001; Brooking, et al., 2009; Clark, et al., 2010; Kim & Taylor, 2008; Smith, et al., 2007; Utter, 2002). For example, in the Clark et al study (2010), 93% of AE students reported that they felt part of AE, 74% felt happier than in their previous school, and 79% felt more hopeful that they will be able to get a job or attend a course in the future than they did in their previous school. Students in AE have also reported feelings of being re-engaged in learning and working harder on school work since they became involved in AE (Brooking, et al., 2009; Clark, et al., 2010).

Werner (1993) and others have described 'turning points' in development, where those who have been immersed in environments involving multiple risk factors become engaged in different settings involving new people, new structures and new expectations and through these and ensuing opportunities make substantial shifts in their lives. Berridge et al. (2001) have suggested that for some young people AE might provide such a 'turning point'.

In sum, the process of being alienated from mainstream education and attending alternative schooling appears to offer risks to healthy development, but may also provide opportunities for vulnerable young people.

## **Why focus on adolescents in alternative schooling?**

Adolescents in alternative schooling are an important group. They have often faced multiple adversities and they have high health and education needs. If those needs are not met, their long term health outcomes and life opportunities are likely to be reduced. The time that these adolescents are in alternative schooling may be a good opportunity to support them.

Adolescents in alternative schooling programmes are frequently described as young people whose needs cannot be met in an ordinary school environment because of behavioural issues. They can also be described as young people who have faced multiple hardships, who have not been served effectively by services in the past, and who continue to be underserved by health services. They deserve

opportunities to have good health and to benefit from meaningful education. This thesis goes on to consider whether a depression intervention can support these students.

## **Chapter 3: DEPRESSION AMONG ADOLESCENTS IN ALTERNATIVE SCHOOLING**

Depressive disorders are among the most significant causes of morbidity and mortality in adolescents (S. Brooks & Kutcher, 2001), and yet they are recognisable and treatable. The current chapter consists of four parts. In the first, I review what is meant by ‘depression’, in the second, I consider why depression is important, in the third part, I review what can be done about depression among adolescents, and particularly what can be done about depression among those in alternative schooling. Finally I describe the development of a computerized cognitive behavioural therapy (cCBT) programme for adolescents with depression.

### **Part 1: What is depression?**

#### **Conceptualising depression**

There is no one definition of depression. With respect to mental or psychological states ‘depression’ is used to refer to a range of experiences from various formally diagnosed disorders to transient passing feelings such as being temporarily sad or down. Even within formal diagnostic systems ‘depression’ is an evolving concept.

‘Depressive disorders’ as defined within contemporary mainstream psychiatric paradigms are heterogeneous psychological disorders centring on ongoing low mood or loss of interest and pleasure in day to day activities. Although conceptualisation of depression as psychological and as primarily related to emotional experiences (rather than perhaps a primarily physical, behavioural or spiritual issue) is relatively recent and relatively western (Durie, 2001; Paykel, 2008), there appear to have been individuals experiencing what we now call depression throughout history. Current evidence supports neither arguments that depression is wholly socially constructed nor an essentialist position that depression occurs in the same way throughout humanity (Paykel, 2008; Redmond, Rooney, & Bishop, 2006). Although the scientific discourse often implies an ongoing search for the essence of depression, depression is regularly described as ‘heterogeneous’ in terms of causal pathways, symptoms and course. It may be that this is a polythetic concept as described by Wittgenstein (Hacker & Schulte, 2009), i.e. something which is discussed as if it is connected by one underlying essential factor but is instead connected by a series of overlapping similarities (or ‘family resemblances’), where no single factor is necessarily common to all.

Within this complexity, there are two widely used systems for defining depressive disorders: 'The Diagnostic and Statistical Manual of Mental Disorders' (DSM) produced by the American Psychiatric Association (American Psychiatric Association, 2000) and 'The International Classification of Diseases' (ICD) produced by the World Health Organization, currently in their 4<sup>th</sup> and 10<sup>th</sup> editions respectively. These provide systems for classifying abnormal, impaired or pathological psychological functioning among individuals based on reported experiences or observable signs. There are many critiques of these systems, including that they may pathologise or medicalise experiences which might be better understood in some other way (Durie, 2011). However, a shared nomenclature has led to major advances in recognition and treatment of mental difficulties.

This thesis follows common practice within New Zealand youth health and mental health services, using the term 'depression' to refer to diagnosed depressive disorders and/or symptoms of depression which are disturbing and are consistent with diagnostic classifications but may or may not meet criteria for diagnosis. DSM and ICD conceptualisations of depression are utilised, as they are widely used and extensively developed, allowing the current work to benefit from the vast body of literature which also uses these systems. However, it is critical to note that these systems are imperfect evolving attempts, mainly led by experts in psychiatry, to classify complex human experiences into categories of disorder.

## **DSM and ICD definitions of depression**

DSMIV and ICD utilise 'mood disorders' as major classifications. These are disorders which are understood to be primarily related to mood or range of feelings. Within DSM they are divided into bipolar and depressive disorders, with the following subcategories of depressive disorders: major depression, dysthymic disorder and depressive disorder not otherwise specified (American Psychiatric Association, 2000). ICD uses similar categories. In each system further specifications detailing severity, recurrence or particular features can be used.

Criteria for diagnoses of depressive disorders using DSMIV require low mood or loss of interest or pleasure and disturbances of thought, emotions or physical functioning such as fatigue, weight change, insomnia or hypersomnia, psychomotor retardation or agitation, feelings of worthlessness or inappropriate guilt, recurrent thoughts of death or suicide, and diminished ability to think (American Psychiatric Association, 2000). These will have been continuing for specific periods of time (depending on the disorder) and having an impact on the person's functioning beyond what would be expected in that person's circumstances (American Psychiatric Association, 2000). ICD10 requires similar symptoms, although for depression low mood (rather than low mood or loss of pleasure) is central and, unlike DSM, bereavement is not an exclusion criterion for diagnosis.

In both systems depressive disorders are 'syndromal'; that is, they are based on clusters of features ('symptoms') which tend to co-occur. As discussed by Paykel (2008), a classification based on symptoms is utilised in medicine where the parameters of a disease are not well established. Syndromes may overlap and there may be different underlying pathologies (Paykel, 2008). Syndromes are often refined as increasing evidence is developed. Indeed, categories of depressive disorders have changed markedly across editions of DSM and ICD. Even distinctions between mood and other disorders are not well understood; co-morbidity between disorders is high and some experts argue that categories do not reflect the actual co-variation of symptoms (Epkins & Heckler, 2011; Kirmayer, 2001; Mellsop, Menkes, & El-Badri, 2007; Mellsop & Smith, 2007). To paraphrase Paykel (2008, p282), findings from recent studies bring into question whether current diagnoses do reflect underlying pathological states or whether these are peripheral and subjective descriptions of neurobiological processes yet to be fully identified.

Although depressive disorders are defined categorically there is strong evidence that these are dimensional issues (D. M. Fergusson, Horwood, Ridder, & Beautrais, 2005). What delineates a person with depression from someone who is not depressed is the number, impact and duration of what would otherwise be considered normal experiences (Mellsop, et al., 2007; van den Oord, Pickles, & Waldman, 2003). New work points to the importance of 'sub-threshold depression' or symptoms of depression that do not meet criteria for disorder but are nevertheless distressing, disabling and predictive of future episodes of depression (Angold, Costello, Farmer, Burns, & Erkanli, 1999; D. M. Fergusson, et al., 2005).

## **Aetiology of depression**

No single causal pathway for depression has been identified, although correlates and predictors have been demonstrated in biological, psychological and social domains. These interact with and contribute to the onset and course of depression through a variety of pathways for different individuals at different times in their life course. Some individuals are more vulnerable than others and this appears to reflect the presence of pre-existing vulnerabilities and/or exacerbating factors. However, relatively little is confirmed about which factors cause (as opposed to co-occur with) depression and how they interact.

Contemporary understandings of depression include the following dimensions:

### ***Genetic risks***

Risk of depression is elevated in adolescents with close relatives who have depression or other psychopathology. This appears to be a function of a number of genetic processes as well as

environmental factors and gene–environment interactions affecting areas such as emotion regulation, reactivity and neurobiological regulation (Rice & Thapar, 2009).

### ***Life stressors and family environment***

Life stressors and difficulties within the family, particularly in early years and where there are multiple negative events, have been shown to be important. These include early attachment difficulties; neglect; abuse; and exposure to violence and parental mental illness, criminality and substance use (Fergusson and Horwood, 2001).

Later social relationships are also important (Epkins & Heckler, 2011). For example, social support is protective against adolescent depression (Rao, Hammen, & Poland, 2010), while poor social skills are both a predictor and a consequence of depression (Rao & Chen, 2009). Difficulties with interpersonal relationships; experiences of loss, trauma and victimisation; deficits in social skills and bullying are proximally related to adolescent depression (Rao & Chen, 2009) and are reported by young people to be important in their depression (Farmer, 2002).

Failure, feelings of letting people down and shame have also been linked to adolescent depression, while the establishment of self efficacy and ‘task accomplishments’ (e.g. positive school experiences) appear to be protective and offer ‘turning points’ or opportunities to mitigate risk (Aro, 1994).

### ***Neurobiological***

Recent EEG studies have highlighted neurobiological differences associated with depression. However, the modifiability of these features is not yet well understood (Nugent, Tyrka, Carpenter, & Price, 2011).

### ***Temperament and personality***

Temperament and personality dimensions associated with neuroticism and inhibited, sensitive, inflexible approaches (Rao & Chen, 2009) are linked to the onset and maintenance of depression. While such traits are relatively stable they can be modified though environment and learning (Rao & Chen, 2009).

### ***Spirituality***

Maori and Pacific Island traditions have emphasised spiritual and familial causes of depression (Durie, 2001; Tamasese, Peteru, Waldegrave, & Bush, 2005). Although spirituality is seldom included in studies of depression, it has been shown to be protective in some settings.

### ***Social and ecological***

The impact of features of society can be difficult to document in research focused on individuals. However there appear to be significant differences in rates of depression in different societies and

social and cultural effects have significant impacts on rates of mental ill health (American Psychiatric Association, 2000).

The impact of colonisation and of alienation from cultural identity is an important factor in depression among Maori (Durie, 2001; McNeill, 2009; T. Stewart, 1997). Colonisation and disenfranchisement have also been highlighted as critical factors affecting the wellbeing of Pacific Island peoples (Mila-Schaaf & Hudson, 2009).

Other social and cultural forces are also important. For example, in some (but not all) studies depression is associated with socio-economic deprivation (Rao & Chen, 2009). Factors such as inequality, increasing deprivation and hopelessness about future life chances might also be important. Some social factors are particularly harmful for particular individuals; for example, growing up in homophobic communities is harmful for same sex attracted young people.

### ***Cognitive Vulnerability***

One of the most significant models of depression is the cognitive theory first proposed by Aaron Beck in the 1960s (Beck, 2008). He hypothesised that individual habits of processing information (cognition) were critical in the aetiology of depression. This theory has gone on to be developed in a sophisticated way. In essence it suggests that people develop schemas (habitual mental representations or ways of seeing the world) that guide attention, expectations and ways of interpreting and responding to events. These schemas develop over time and become automatic (fast and not requiring conscious attention) and global. Negative (or depressogenic) schemas might develop in response to difficult experiences and mean that experiences are routinely interpreted negatively. Once depressogenic schemas are activated, individuals are disposed to developing persistent negative ways of seeing the world, themselves and the future. Such a 'negative triad' of beliefs predisposes one to depression in the presence of stressful events. While schemas are largely automatic, people can notice and alter these persistent patterns and thus alter their mood.

This theory has formed the basis of cognitive and cognitive behavioural therapies which have been widely tested and appear to be effective treatments for depression (Butler, Chapman, Forman, & Beck, 2006). Recent work has begun to explore how cognitions interact with neurobiological changes (Beck, 2008).

A related theory is that of 'learnt hopelessness' proposed by Abramson and others (Abramson, Metalsky, & Alloy, 1989). This proposes that individuals develop a depressive 'attribution style', where negative events are attributed to stable internal, global characteristics (for example "I failed the maths test because I am so stupid"), while positive events are interpreted as transient and externally caused ("I passed because that was a really easy test for once"). This theory postulates that a negative



attribution style tends to lead to helplessness, hopelessness, and thus depression in the face of adversity. Hopelessness has indeed been linked to depression and aspects of attribution style are addressed in many cognitive therapies (Weersing & Bren).

Other cognitive vulnerabilities include rumination, unproductive problem solving styles and self criticism. For example:

- Rumination and co-rumination (frequently discussing and rehashing problems with peers) (Stone, Hankin, Gibb, & Abela, 2011) have been identified as predictive of depression. Significantly, new findings suggest that people who ruminate a lot might gain less benefit or even suffer harmful effects from traditional cognitive self help approaches (Haefffel, 2010).
- Disengaged responses or 'emotion focused coping styles' such as avoidance, self blame or denial are associated with increased depression (Rao & Chen, 2009; Rice & Thapar, 2009), while 'engaged coping styles' such as active problem solving to address sources of stress appear to be more helpful.
- Rice and Rawal (2011) quote evidence from adult studies that tolerating negative affect through techniques of acceptance and mindfulness is an important and modifiable skill in emotion regulation. This may offer promise for addressing adolescent depression.

## **Measuring depression**

There is no single measure of depression. Rather a number of self rating scales, structured clinical interviews and other informant rating scales are used. There are adolescent specific scales although adult measures are sometimes used with young people (Petersen et al., 1993). There are some efforts to develop measures for use in specific cultural settings; however, this is the exception rather than the rule (US Department of Health and Human Services, 2001).

Scales and interviews each utilise observed or, more commonly, reported symptoms. If an individual is not particularly focusing on their feelings, or if they do not wish to address such matters in the context in which they are being measured, this might lead to under-recognition of depression. Typically, measures of symptoms are not objective, but implicitly require comparison to some norm (for example, "am I feeling sad?" begs comparison to how I normally feel, what I see around me or to what I consider normal or perhaps ideal). Subjective measures might lead to under-reporting where unpleasant feelings are normal for a respondent or are very common in their context (S. Brooks & Kutcher, 2001). Most measures of depression are closely linked to DSM or ICD concepts of depression. This might also lead to under-reporting among individuals who experience depression in different ways (e.g. as primarily a physical or spiritual issue rather than as a psychological disturbance).

## **Differences among groups of people**

There are differences in rates of depression among different groups of people. Some of these are likely to reflect differences in rates of disorder, while some reflect differences in ways of understanding, describing, tolerating or responding to similar experiences (Kirmayer, 2001; Paykel, 2008; Tapsell & Mellsop, 2007).

In terms of gender, males are often considered to be more likely to show anger and frustration as signs of depression, while females may be more likely to express sadness and to talk directly about emotions (Brownhill, Wilhelm, Barclay, & Schmied, 2005).

Among ethnocultural groups in New Zealand a number of investigations have suggested that Maori (Durie, 2001) and some ethnic minorities (Parker, Chan, Tully, & Eisenbruch, 2005) may be more likely to complain of physical or somatic symptoms, whereas 'psychologising' distress (White, 1982) or focusing on emotions (Paykel, 2008) may be a relatively Western approach. Western thought has a long tradition of separating body, mind and spirit and of valuing one's personal experience. Durie (2002) suggests contemporary western Eurocentric cultures consider personal happiness a norm or right. In this context it might be common to be interested in one's own emotional wellbeing, to be active about noticing and addressing unpleasant emotions and to articulate emotional and physical concerns separately. In fact Asian peoples (Parker, et al., 2005), African peoples (Paykel, 2008), young people (Rao & Chen, 2009) and men (Brownhill, et al., 2005) have all been described as being likely to somatise depression and to be less likely (than whoever provides the norm for psychiatry) to discuss emotions.

Given that the majority of young people in alternative schooling in New Zealand are of Maori or Pacific Island ethnicity and all are adolescents, it is appropriate to consider depression among Maori and Pacific groups and among adolescents.

### ***Maori concepts of depression***

Maori concepts of mental health and depression are varied (T. Stewart, 1997). Traditional concepts are embedded within Maori epistemologies and Maori concepts of health. To those in western traditions, Maori traditions of thinking are sometimes described as emphasising synthesis and holistic approaches, rather than necessarily breaking down complex wholes into separate components (Durie, 1994). As a concrete example, words for feelings in Te Reo (the Maori language) do not necessarily seek to separate body and mind. Maori concepts of health also utilise holistic approaches. There are a number of models developed to express these concepts (McNeill, 2009). These include the Te Whare Tapa Wha model (Durie, 1982). In brief, this model is that te taha hinengaro (translated as 'psychological health'), te taha wairua (spiritual health), te taha tinana (physical health) and te taha whānau (family health) are

four dimensions that together build a state of health. As in the walls of the ancestral meeting house, each of the four dimensions is necessary and without one the whole does not function. Te Wheke (Pere, 1982) uses the metaphor of the octopus where the following interdependent ‘tentacles’ together create a healthy person: Wairuatanga (spirituality); Mana ake (individual uniqueness); Mauri (life force); Hā a kui ma a koro ma (traditional cultural legacy); Taha tinana (physical health); Whānaungatanga (family connections); Whatumanawa (emotional aspect) and Hinengaro (mind). Each of these models emphasise that there are many aspects to wellbeing, and that individual mental health is not typically considered in an isolated way.

These concepts are somewhat different from western traditions and might mean that western health practitioners and psychometric measures fail to recognise Maori experiences of depression. Indeed in a study of General Practitioners (GPs) in Auckland, Arroll and others (2009) found that GPs considered that they might be more likely to miss depression among Maori than among New Zealand European clients.

### ***Pacific concepts of depression***

Pacific peoples in New Zealand come from many different cultural communities. There is no one Pacific model of mental health or depression (Mila-Schaaf & Hudson, 2009). Tamasese and others (2005) emphasise that to understand Samoan ideas of mental health one needs to understand Samoan concepts of self. These include an emphasis on relationships rather than on individuals, i.e. the self exists and has meaning in relation to others, and on holistic approaches, which include spirituality and tend not to separate mind and body.

### ***Depression among adolescents***

Within western psychological traditions depression was not considered important among adolescents until the 1970s (Rao & Chen, 2009). This was a function of ideas such as turmoil or ‘storm and stress’ being normative in adolescence and the view that the superego was not yet sufficiently mature to allow true depression. Since that time it has become clear that most young people navigate the changes of adolescence without serious trauma, while others do suffer from depression and ill health (Petersen, et al., 1993).

Concepts of depression in adolescents have developed from those articulated with reference to adults. Although there are many similarities, there are differences between childhood, adolescent and adult depression in terms of prevalence, relative risk for males and females, prominent risk factors, symptoms, ways of responding to feelings of depression and rates of recurrence (Rice & Rawal, 2011).

Depression is thought to be relatively rare in children and occurs at similar rates in males and females. From the onset of puberty there is an almost linear increase in rates of major depression until around

19 years when adult rates are reached (Davey, Yücel, & Allen, 2008; Rao & Chen, 2009). The increase is particularly concentrated among females, so that by the end of adolescence male: female rates are about 1:2 to 1:3 (Rao & Chen, 2009). The causes of this rapid change and the reasons for increasing gender differences are not known, although biological, psychological and social pressures and interactions with developmental vulnerabilities are being explored in the contemporary literature (Davey, et al., 2008; Rao & Chen, 2009).

Salient risk factors for depression differ somewhat between children, adolescents and adults. Among adolescents, life stressors may play a more important role than they do in older age groups and of these social relationships may be particularly important (Davey, et al., 2008).

Differences in the presentation of depression among adolescents compared to adults have also been reported. Adolescents are particularly likely to report irritability and anger (Brent & Birmaher, 2002; Parker & Roy, 2001). Although irritability is noted as a possible sign of depression in DSMIV, anger is not salient in contemporary definitions and measures of depression. In a phenomenological study Farmer (2002) reported no mentions of sadness in adolescents' descriptions of their experience of depression but fatigue, relationship difficulties and overwhelming feelings of anger were prominent. Adolescents also may differ from adults in emotional reactivity or the apparent stability of emotional lows. Sadness may be less prominent than boredom and loss of interest or pleasure (Brent & Birmaher, 2002). These differences may mean that depression is under recognised among young people.

## **Part 2: Why is depression important among adolescents in alternative schooling?**

Depression is important among adolescents in alternative schooling as it is common, harmful and amenable to change.

### **Rates of depression**

Depression is common among adolescents and appears to be particularly common among young people in alternative schooling. That said, prevalence estimates of depression do vary with the measure by which they are assessed, who is the informant, the setting (e.g. community or clinical samples), the time period of reference and the age group included. In the Christchurch longitudinal study rates of depression among 15 year olds were 9.2% for females and 3.3% for males, while at 18 years 26.5% of females and 9.7% of males had experienced depression (D. M. Fergusson & Horwood, 2001). In the 2007 New Zealand Adolescent Health Survey of nearly 10,000 secondary school students,

14.7% of females and 6.9% of males had clinically significant depressive symptoms at the time of the survey (Fortune et al., 2010).

As reported in Chapter two, New Zealand AE students have elevated rates of depressive symptoms compared to school students (Clark, et al., 2010). International literature has also reported elevated rates of depression among young people in alternative schooling environments. For example in a small study utilising clinical interviews with students in two Australian AEs, 40% of students had clinical depression (Murrihy, 2010), while Place and others (2000) found that in a UK school for emotionally and behaviourally disordered 6-13 year olds, 24% had depression using DSMIII-R criteria. Also in the UK, Hackett and others (2010) reported that among pupils in schools for emotionally and behaviourally disordered pupils, 58.6% scored in the abnormal range for emotional problems (Hackett, et al., 2010). In the US rates of mental disorder have been identified as higher among young people in a school for pupils with serious emotional disturbance than among young people in mental health services (Garland et al., 2001).

Rates of depression may be under-reported among adolescents in alternative schooling due to measurement issues such as the use of western measures in diverse communities and the use of subjective measures when norms within AE may reflect the clustering of 'at risk' students.

Many adolescents in alternative schooling have other mental health issues in addition to depression. Some of the most common reasons alternative schooling students have been excluded from mainstream education relate to violent or aggressive behaviours in school (K. Johnson & Taliaferro, 2012; O'Brien, et al., 2001; Stevens, et al., 2005). Not surprisingly, behaviour problems including conduct disorder are reported to be especially high among alternative schooling students. For example Murrihy (2010) identified 100% of her small sample of AE students to have conduct disorder or oppositional defiant disorder. Also in a small study involving clinical interviews, this time in the UK, Cassidy, James and Wiggins (2001) found 78% of AE students had conduct disorder.

Thus overall the literature suggests that rates of depression among adolescents in alternative schooling are high and rates of behavioural problems are very high.

## **The impact of depression**

Depression is an unpleasant experience for the person who is experiencing it and often for those around them (Farmer, 2002). The symptoms of depression make important developmental tasks such as achieving at school, making future plans and forming intimate relationships challenging. Depression in adolescence predicts future depression (Dunn & Goodyear, 2006; D. M. Fergusson, et al., 2005; D. M.

Fergusson & Woodward, 2002), increased risk of bipolar disorder, anxiety disorders (D. M. Fergusson, et al., 2005; D. M. Fergusson & Woodward, 2002) and suicidal behaviours (D. M. Fergusson, et al., 2005; Fombonne, Wostear, Cooper, Harrington, & Rutter, 2001). Although not necessarily causal of each of these, adolescent depression is associated with a range of additional health risks and difficulties, including:

- increased substance use or abuse (D. M. Fergusson & Woodward, 2002; Rao & Chen, 2009)
- delinquency or criminal behaviour (Rao & Chen, 2009)
- health risk behaviours (Testa & Steinberg, 2010)
- increased risk of early unplanned pregnancy or early parenthood (D. M. Fergusson & Woodward, 2002; Rao & Chen, 2009)
- increased physical ill health (Keenan-Miller, Hammen, & Brennan, 2007)
- increased health service use (Keenan-Miller, et al., 2007).
- problems in interpersonal relationships (Fombonne, et al., 2001; Rao & Chen, 2009)
- problems in school performance and social, emotional and cognitive development (Rao & Chen, 2009)
- educational underachievement (D. M. Fergusson & Woodward, 2002)
- decreased employment prospects, increased unemployment or work impairment (D. M. Fergusson & Woodward, 2002; Keenan-Miller, et al., 2007).

The impact of dysthymia and of sub-threshold depression has been less studied than that of major depression. However, there are indications that these are harmful in similar ways. Some studies (e.g. Fergusson et al, 2005) suggest that the harm from sub-threshold depression in adolescence is close to that of diagnosable disorder.

Many brain systems mature and become less malleable through adolescence; thus the development of persistent neurological patterns associated with depression might be particularly harmful at this formative stage. Similarly the establishment of behavioural and cognitive patterns of depression might also be particularly harmful in this period of life when many habits of adult behaviour appear to be established (Meyer, Chrousos, & Gold, 2001).

The impact of depressive symptoms might be particularly important for adolescents in alternative schooling. As described earlier (chapter 2, part 2), risks to healthy development are typically cumulative, with exposure to multiple risks being particularly harmful (D. M. Fergusson & Lynskey, 1996; Masten & Obradović, 2006). For example, depression in combination with conduct disorder is more strongly associated with suicidal behaviours than either disorder on its own (Vander Stoep et al., 2011). Brooking and others (2009) noted that emotional dysregulation was common among AE students. If this is so, then relatively extreme behaviours are likely in response to unpleasant emotions

in this group. The anger and hopelessness associated with adolescent depression may be particularly harmful among adolescents somewhat disengaged with mainstream social norms. Young people who already face challenges with educational achievement and have reduced access to future opportunities may risk increased impact from concentration and motivational difficulties associated with depression. Further, family difficulties are common among alternative schooling students (Brooking, et al., 2009), which might mean that getting help for depression (which often begins through families) is particularly challenging. In sum, depression is associated with increased risks of a range of negative outcomes and may be particularly harmful for young people in alternative schooling.

## **Why prioritise depression?**

As discussed in Chapter 2, rates of health and social difficulties are high among adolescents in alternative schooling; these groups are currently poorly served by health services and yet they are relatively easy to locate while they are in alternative schooling. These factors provide both the imperative and the opportunity for health and social services to address their needs. Approaches to develop and support adolescents in alternative schooling can be comprehensive, addressing a range of difficulties, or can address specific concerns such as depression. To draw a line between comprehensive and specific treatments is partly an artificial exercise, as most comprehensive approaches include components to address specific problems and few would advocate that efforts to address isolated issues should be carried out without co-ordination.

While not precluding addressing other needs, nor devaluing comprehensive approaches, addressing depression in particular is appropriate for mental health providers as:

- there are high rates of depression in this group
- depression might be particularly harmful for adolescents in alternative schooling
- reducing depression might have a positive impact on other issues for adolescents in alternative schooling
- depression is something which mental health services are mandated to respond to
- depression specific treatments appear to be effective in reducing depression, whereas more generic programmes have not been shown to have strong effects on depression
- there are treatments for depression which may be acceptable and effective for adolescents in alternative schooling and which might be feasible to implement.

## **Part 3: Treatment and prevention of depression among adolescents**

In this section I consider interventions to reduce depression among adolescents, barriers to accessing treatment and the use of computerised therapies for depression.

Interventions to reduce depression span from efforts to prevent it, to early intervention among those with mild symptoms or early signs, to treatment and relapse prevention among those with mild, moderate or severe depression (O'Connell, Boat, & Warner, 2009). Although conceptually prevention and treatment are regarded as different activities, there are considerable overlaps in what works for treating and preventing depression. Interventions to reduce the impact of depression may also be categorised into those which address proximal risks (such as depressogenic thinking) and those which address distal risks (such as infant-parent relationships) and into those which address individual vulnerabilities (as do antidepressants and therapy) and those which operate at a population level (for example, reducing discrimination). Distal interventions might have a significant impact across a range of negative outcomes and population interventions may have an impact for a large number of people. However, it can be difficult to show the effect of long term or population interventions in scientific studies which prioritise randomisation and are typically short term. Currently, evidence regarding interventions for depression focuses mainly on treatments which address proximal risks in individuals.

### **Treatment**

The mainstays of treatment for adolescent depression are antidepressant medications and psychotherapies (Merry & Stasiak, 2011), although there is emerging evidence that regular exercise might have a small effect (Larun, Nordheim, Ekeland, Hagen, & Heian, 2006).

Antidepressant medications have been widely used. Systematic reviews for the Cochrane Collaboration have suggested no or limited benefits for adolescents using tricyclics (Hazell, O'Connell, Heathcote, & Henry, 2002) and more promising results for selective serotonin re-uptake inhibitors (SSRIs) (Hetrick, Merry, McKenzie, Sindahl, & Proctor, 2007). However, there are safety concerns for each of these (in particular that they might increase suicide ideation and attempts) and the New Zealand Guidelines Group recommend that antidepressant medication not be initiated in young people in primary care except in consultation with a child and adolescent psychiatrist (New Zealand Guidelines Group, 2008). Evidence based psychotherapy is often recommended as a better first option for mild to moderate depression among young people (Hetrick, Simmons, Thompson, & Parker, 2011; National Institute for Health and Clinical Excellence, 2005).



In terms of psychotherapies, one of the most tested interventions is CBT. Reviews have identified that this is effective or promising for depression, generalized anxiety disorder, panic disorders, social phobia and posttraumatic stress disorder, as well as for issues such marital distress, anger, somatic disorders, and chronic pain (Butler, et al., 2006). Many studies have reported that CBT is effective for adolescent depression and some have reported large effect sizes (David-Ferdon & Kaslow, 2008). However recent meta analyses have reported smaller effect sizes for therapies, including CBT (Watanabe, Hunot, Omori, Churchill, & Furukawa, 2007; Weisz, et al., 2006). This appears to be at least in part because of the increased proportion of trials comparing the effects of therapy to an active comparison, rather than just waitlist control. This is an important point as there are often significant, though perhaps poorly sustained, improvements in depressive symptoms in response to placebo treatments (Andrews, 2001).

In the methodologically rigorous meta-analysis by Weisz and others (2006) there was little difference between cognitive and non-cognitive approaches overall. However, they identified five studies with high effect sizes; three of these were of CBT, one was a cognitive bibliotherapy and one a relaxation intervention. They highlighted variation within therapeutic modalities and the importance of non-specific treatment effects which might be the most powerful change agents; these include the expression of hope, the idea that depression is treatable and the use of homework or practising skills (McCarty & Weisz, 2007; Weisz, et al., 2006).

Other psychotherapies that have been supported in trials for adolescent depression include Interpersonal Therapy (David-Ferdon & Kaslow, 2008) and Behavioural Activation (Kanter et al., 2010). New therapies which emphasis acceptance and mindfulness show promise in adults (Hofmann & Asmundson, 2008) and may prove to be helpful in young people (Liehr & Diaz, 2010).

These mixed findings have led to calls for the identification of mediators of effect and of active elements in therapies across modalities (La Greca, Silverman, & Lochman, 2009; McCarty & Weisz, 2007). Heterogeneous findings of effects of interventions for depression also suggest the need for greater individualisation of treatment (Katon, Unützer, & Russo, 2010).

With the caveats that all CBT might not be equal, and that effective elements of therapy might be found across a range of modalities, CBT remains one of the most recommended therapies for depression (Cheung et al., 2007; Hetrick, et al., 2011; New Zealand Guidelines Group, 2008; Thapar, Collishaw, Potter, & Thapar, 2010) and meta analysis suggests that overall CBT should be a first line psychosocial treatment of choice (Tolin, 2010).

## Prevention

Prevention efforts can be categorised as 'universal' (for everybody in a population or a whole group in a population, regardless of individual risk) or as 'targeted' (for those at higher risk of disorder). Targeted interventions can be further identified as 'selective' (for groups or individuals with elevated risk) or 'indicated' (for individuals with early signs) (O'Connell, et al., 2009). Indicated prevention can be considered to overlap with early intervention approaches (Merry, McDowell, Hetrick, Bir, & Muller, 2011; O'Connell, et al., 2009). Promotion of good mental health, resilience or coping skills might also be placed on this spectrum, although this is debated (O'Connell, et al., 2009).

Efforts to prevent depression could feasibly include interventions to address any of the causal pathways identified as important in the aetiology of depression. There have been trials of comprehensive school-wide approaches (Bond et al., 2004; Kasunic, Davis, Noonan, Leung, & Sneddon, 2005) which have not shown significant effects on depression to date. However, most adolescent depression prevention trials are of psychotherapeutic or information based interventions offered universally or to young people in identified risk groups.

Universal depression prevention programmes for adolescents are typically offered in schools and are mainly based on cognitive behavioural therapy or components of cognitive behavioural therapy (Calear & Christensen, 2009; Merry, et al., 2011) or are educational programmes (Merry, et al., 2011). They are usually facilitated by teachers or external professionals (Calear & Christensen, 2009; Merry, et al., 2011) although there are recent trials of computerised prevention interventions in schools (Calear & Christensen, 2009; O'Kearney, Gibson, Christensen, & Griffiths, 2006; O'Kearney, Kang, Christensen, & Griffiths, 2009).

Targeted interventions which have been tested include programmes for young people who have sub-threshold symptoms of depression, behavioural problems or challenges such as parental divorce (Calear & Christensen, 2009; Stevens, et al., 2005), parental substance use or mental illness (Stice, Shaw, Bohon, Marti, & Rohde, 2009). Most of these are group programmes and, again, most are based on CBT or components of CBT (Merry, et al., 2011).

Recent meta analyses have reported that depression prevention programmes may reduce the onset of depressive disorders and thus hold promise for reducing the population impact of depression (Calear & Christensen, 2009; K. A. Collins & Dozois, 2008; Merry, et al., 2011; Stice, et al., 2009). Some reviews have reported more effect for targeted interventions than universal ones (Calear & Christensen, 2009; K. A. Collins & Dozois, 2008; Merry & Spence, 2007; Stice, et al., 2009). However, in their meta-analysis which only included randomised controlled trials, Merry et al (2011) did not find universal programmes to be inferior. To date there are few studies which are methodologically rigorous (e.g. utilising assessor

blinding and active control groups) (Merry, et al., 2011), few therapeutic modalities have been tested (most are CBT based) and findings are heterogeneous (Calear & Christensen, 2009; Merry, et al., 2011). Thus it is premature to make conclusions regarding which therapeutic modalities are most effective.

In conclusion, educational and psychotherapeutic programmes, most of which have been based on CBT, have been shown to have some significant effects in preventing depression.

## **Barriers to treatment**

Even though interventions have been shown to reduce depression, the health impact of these is limited (Andrews, et al., 2010). Two decades ago, Fergusson et al (1993) reported that up to 80% of young people with depression did not get treatment. More recent studies suggest that the majority of young people with depression still do not get treatment (Zachrisson, et al., 2006). Barriers to treatment are many and include person-centred barriers, barriers related to the experience of depression and barriers related to how health services are delivered.

Person-centred barriers include not identifying that one is depressed (Coe, 2009; Zachrisson, et al., 2006). This appears to be particularly common among males, younger adolescents (Wright & Jorm, 2009), people with limited formal education (Ministry of Health, 2010) and Maori (Ministry of Health, 2010). Even if an individual realises that they are depressed, they might not consider that help is available or that treatment may help (Vanheusden et al., 2009), they might feel too embarrassed or ashamed to seek help (J. E. Collins, Winefield, Ward, & Turnbull, 2009) or they might not wish to use mental health care or therapy (Christensen, Leach, Barney, Mackinnon, & Griffiths, 2006; J. E. Collins, et al., 2009; Rickwood, Deane, & Wilson, 2007; Wright, Jorm, Harris, & McGorry, 2007). Indeed many young people report that they would prefer self-help, internet based information or support via people they know rather than seeking professional mental health care (Rickwood et al, 2007; Farrand et al, 2006). Person-centred barriers to getting help for depression such as these are generally particularly common among young people and among males (Jorm et al., 2006).

Depression and psychological distress appear to be 'help negating' among young people; i.e. when young people are depressed or distressed, they appear to be less likely to seek help than young people who are not down imagine that they would be (Wilson, 2010; Wilson, Rickwood, & Deane, 2007). This may be related to the hopelessness, withdrawal or reduced motivation associated with depression and distress (Wilson & Deane, 2010).

There are also issues related to how health services are delivered that may make it difficult for adolescents to access treatments for depression. These barriers include actual and perceived costs of

services, inconvenient opening hours or location and waiting lists for services (Adolescent Health Research Group, 2008a; Bernard et al., 2004; Booth et al., 2004; T. Fleming & Elvidge, 2010). Even when young people are seen by health services, professionals may fail to carry out consultations in ways that support them to disclose sensitive issues. For example, in a nationally representative sample of 16-20 year olds in Switzerland, only 13% of those who needed help for sadness or depression did seek help for it from a health care provider, even though 80% of them regularly consulted their General Practitioner (GP) (Mauerhofer, Berchtold, Michaud, & Suris, 2009). Health professionals may not build relationships that adolescents consider sufficiently close or trusting to discuss intimate issues (Bernard, et al., 2004) or professionals may not raise topics or ask questions which prompt disclosure (Tylee, Haller, Graham, Churchill, & Sanci, 2007). Even if symptoms are disclosed, providers may fail to recognise depression (Zwaanswijk, Verhaak, Bensing, van der Ende, & Verhulst, 2003).

When depression is identified with a health professional, access to evidence based treatments are limited, particularly for some groups. There are insufficient therapists trained in CBT in New Zealand (Bir et al, 2007) and elsewhere (Andrews, et al., 2010). This may be particularly acute in remote or poorer communities. For example Shapiro, Cavanagh and Lomas (2003) reported a 20-fold discrepancy in availability of accredited CBT therapists between the most and the least served population deciles in the UK.

Many people terminate face to face CBT or other psychotherapeutic treatments earlier than is considered necessary for effective treatment (Andrews, et al., 2010; Westmacott, Hunsley, Best, Rumstein-McKean, & Schindler, 2010; Williams & Martinez, 2008). The reasons for this are not well understood. For some, early termination appears to be related to improvement in symptoms, while others leave because of dissatisfaction with treatment or reasons such as inconvenience (Westmacott & Hunsley, 2010; Westmacott, et al., 2010). Early drop out from therapy has been reported to be higher among younger, more distressed clients who posed higher risks to others (Saxon, Ricketts, & Heywood, 2009) and drop out because therapy was not helping has been reported to be high in lower income than in wealthier clients (Westmacott & Hunsley, 2010).

In sum, there are multiple barriers to evidence based treatments, many of which disproportionately affect young people, those in low socio-economic communities and those who are not highly educated.

## **Computerised CBT**

Computerised psychotherapies are psychotherapies (hereafter 'therapies') delivered via computer programmes. They can be available freely, e.g. over the internet, or offered via service providers such as GPs and may or may not involve direct support from a therapist or other helper. Computerised

therapies differ from therapist led interventions carried out online as computerised therapies are pre-programmed and can be completed without the intervention of a therapist. Computerised therapies have developed in recent years in response to factors such as the limited availability of therapists to deliver evidence based interventions, the popularity of self-help approaches and the increasing availability and flexibility of information technology (I. Marks & Cavanagh, 2009). To date, most computerised psychotherapies have been for anxiety and mild to moderate depression among adults (Kaltenthaler & Cavanagh, 2010), although there are also computerised therapies for other psychological and physical health conditions (Kaltenthaler & Cavanagh, 2010; I. Marks & Cavanagh, 2009). Most computerised therapies for depression are based on CBT (Kaltenthaler & Cavanagh, 2010). The structured and instructional nature of CBT means that it is relatively simple to translate to computerised programmes (Kaltenthaler & Cavanagh, 2010).

Andrews and others carried out a meta analysis of 22 randomised controlled trials of cCBT programmes for depression or anxiety among adults (Andrews, et al., 2010). They reported that cCBT was effective for both anxiety and depression, the mean effect size was good and in the five studies comparing computerised and face to face CBT, both approaches were equally effective. People who participated in trials were satisfied with cCBT and completion of cCBT programmes in trials was generally good. This review is consistent with earlier reviews (Kaltenthaler, Parry, Beverley, & Ferriter, 2008; I. Marks & Cavanagh, 2009; Spek et al., 2007; Titov, 2007).

Computerised cCBT has frequently been considered as a treatment for those with mild to moderate depression as part of a 'stepped care' approach, while individual clinical interventions are recommended for those who have more severe disorders or do not respond to less intensive interventions (Bower & Gilbody, 2005; Cavanagh et al., 2006; Learmonth, Trosh, Rai, Sewell, & Cavanagh, 2008; Williams & Martinez, 2008). However, cCBT has been used with clients with different levels of severity and meta analysis has identified cCBT to be equally effective in community, primary health and community mental health service settings (Richards & Richardson, 2012).

Computerised CBT can potentially offer some benefits over face to face approaches. Computerised CBT programmes may have large development costs; however, if they are implemented widely the cost per person can be low (Andrews, et al., 2010; Williams & Martinez, 2008). The use of computerised programmes can ensure treatment fidelity and can allow rapid updates of treatment (Kaltenthaler & Cavanagh, 2010). Measures of users' mood and utilisation of cCBT can be embedded into cCBT programmes and can be programmed to provide regular updates to users and clinicians (I. Marks & Cavanagh, 2009). Computer programmes can utilise ways of working and learning that some people prefer over talking based approaches (Williams & Martinez, 2008). Computerised CBT can offer convenience: users may be able to choose when and where they access it (I. Marks & Cavanagh, 2009).

Some clients have preferred cCBT over face-to-face therapy because of reduced stigma or embarrassment (I. Marks & Cavanagh, 2009). Being essentially structured self help, cCBT can promote mastery and resourcefulness (Kaltenthaler & Cavanagh, 2010).

In these ways cCBT offers opportunities to overcome many of the identified barriers to evidence based treatments for depression. Where cCBT must be accessed via health care professionals it might reduce barriers associated with a lack of specialist therapists. Where cCBT can be accessed without a health provider (e.g. if it is freely available on-line) barriers associated with shame and embarrassment can also be reduced. If cCBT is provided routinely to groups, for example to adolescents in schools, then personal barriers such as not recognising that one is depressed are also reduced.

However, challenges for cCBT have been identified. Users do require access to computers and sufficient computer skills to use the programmes. Although acceptability of cCBT is high among participants in trials of cCBT, study volunteers may not reflect the population (Kaltenthaler et al., 2008). Computerised CBT might not be appealing among people who are not very comfortable with computers, those who have had little information about cCBT or those who would prefer alternatives such as face to face therapy (Beattie, Shaw, Kaur, & Kessler, 2009; N. Mitchell & Gordon, 2007).

Early drop out from treatment is high in some studies of computerised therapy (Melville, Casey, & Kavanagh, 2010), particularly where open access to web based interventions is used (Christensen, Griffiths, & Farrer, 2009). Programmes delivered with some personal support have had higher rates of completion and higher effect sizes than those that are entirely self-directed (G. Marks, 2007; Spek, et al., 2007; Titov, Andrews, & Sachdev, 2010). However, for structured computerised programmes, support need not be provided by highly trained therapists (I. Marks & Cavanagh, 2009). Rather, supportive encouragement appears to be what is required; this might require just a few minutes a week and could be offered by telephone or online (Williams & Martinez, 2008). Alternatively, computer programming features might be enhanced to provide encouragement (Christensen, et al., 2009).

Therapists have expressed concerns that cCBT might be less effective than face to face therapy (Whitfield & Williams, 2004; Williams & Martinez, 2008), that clients might not be safe on a computerised programme (Stallard, Richardson, & Velleman, 2010), that computerised programmes might not be sufficiently responsive to individual needs (Stallard, Richardson, et al., 2010) and that computerised therapy lacks what might be the most important component of therapy: the therapeutic relationship (Peck, 2010). However it is not clear to what extent these concerns are correct (Peck, 2010; Williams & Martinez, 2008).

Thus, although some questions and concerns require consideration, cCBT has been shown to be effective for adults with depression. Computerised CBT appears to offer advantages over face to face

therapy for some users and to offer opportunities to reduce barriers to evidence based therapies for depression.

## **Computerised CBT for adolescent depression**

I carried out a literature search for cCBT programmes for depression among adolescents in mid 2008 when I began this research. The search terms are included in Appendix B. Medline, PyschInfo and Embase databases were searched. Abstracts for all identified articles were reviewed. Articles were excluded if they reported therapist led interventions carried out online, rather than pre-programmed therapies which could potentially be completed without the intervention of a therapist. Those which reported results of a trial, study or evaluation of a cCBT programme for depression among adolescents in a peer reviewed publication and included a measure of depression or depressive symptoms were retrieved. Reference lists of included articles were scanned for relevant references and I checked for more recent papers citing the included articles. In total, two trials of computerised CBT programmes for adolescent depression were identified.

The first of the cCBT studies, Van Voorhees, Ellis, Stuart, Fogel, and Ford (2005), was an open trial pilot study of a web-based self-directed depression skills training program (later known as 'CATCH-IT') with 14 young adults (18-25 years) in the USA. The programme consisted of 14 modules based on CBT, Interpersonal Therapy and Behavioural Activation. It was preceded by a motivational interview with a GP. Participants had lower depressive symptoms immediately post intervention than they did prior to beginning the programme (effect size 0.43), (Van Voorhees, et al., 2005). The programme was not available for public use.

The second study, O'Kearney et al. (2006) investigated the use of 'MoodGYM' in a boys school in Victoria, Australia. MoodGYM is an online, freely available programme initially developed for adults. It utilises questionnaires, information, demonstration and exercises based on CBT. It is mainly delivered via written text on the computer screen. Participants in this study were not seeking assistance and were not necessarily depressed. Only 40% of the participants completed more than 3 modules of the 5 module programme. Small positive effects on depressive symptoms were reported immediately post intervention. However, these effects were not sustained at follow up.

Although both studies reported positive effects at post intervention, only the MoodGYM study was a randomised controlled trial (O'Kearney, et al., 2006) (O'Kearney, et al., 2006) and neither study provided evidence of sustained effects. MoodGYM did not appear to be engaging for adolescents and

CATCH-IT was not publically available. Thus there was a lack of evidence regarding the use of cCBT with adolescents and a lack of available programmes for adolescents.

## **Interventions for depression among adolescents in alternative schooling**

I carried out a systematic review for any interventions for depression among adolescents in alternative schooling programmes for those alienated from mainstream education. Given that this is a specialist area I included both prevention and treatment programmes, and included programmes which were not necessarily focused on depression but did include symptoms or diagnosis of depression as an outcome measure. I included open trials and evaluations and used no language limitations. I limited findings to peer reviewed publications published from 1995. 1995 was selected as a cut off as criteria for older alternative schooling programmes might be difficult to determine and in New Zealand, the UK and the US there have been significant changes in AE provision since the mid 1990s. Programmes specifically for pregnant or parenting teens were excluded as this group might have different needs. The search was carried out in September 2008.

The following databases were searched: Medline in process and non-indexed citations, Medline daily, and Medline 1946 to present (this includes Cochrane reviews); CINAL plus; ERIC; EMBASE; PsychINFO plus and Social work abstracts plus. Search terms are specified in Appendix B. Search terms were inclusive as there are not specific widely used MeSH terms for adolescents in alternative schooling programmes and I did not wish to miss relevant programmes. In addition, reference lists of relevant papers were scanned; papers that were relevant were checked for more recent publications citing them and a brief Google search was carried out. Abstracts were reviewed for all identified studies. Using a pre-established check list I excluded papers that did not address adolescents, did not report findings for participants in programmes for young people alienated from or excluded from mainstream schooling, did not include a measure of depression or depressive symptoms, did not report the impact of an intervention, or were not peer reviewed.

This strategy resulted in just two studies (see Table 4). The first, Carpenter-Aeby and others (2005) concerns a 'Family, School, Community Collaboration' intervention utilised universally with students in an alternative school in the USA. This is a broadly defined programme with no specified intervention for depression in particular. This study reports positive outcomes for depression in 2 out of the 5 years evaluated and non significant findings for the other three years. It is difficult to establish the importance of their findings given the lack of detail reported.



The second study (Wignall, 2006) reports an impressive reduction in depressive symptoms as well as externalizing behaviour following a group CBT intervention. This was an indicated intervention for 17 AE students with depressive symptoms and problem behaviour.

Both of these studies are pre-post intervention evaluations with no control group and with no follow up measures. Both studies report findings only for students who completed or almost completed the programme. Thus there was not sufficient research to identify approaches that are effective in reducing depressive symptoms among adolescents in alternative schooling.

### **Computerised CBT: an opportunity for adolescents in alternative schooling?**

In this chapter I have shown that depressive disorders and symptoms of depression are common and cause significant difficulties for adolescents. Interventions have been developed which are helpful in treating or preventing depression; however, many people who may benefit from such interventions do not receive them. Computerised CBT is effective for depression among adults, and computerised therapies offer opportunities to reduce some of the barriers to treatment for depression; however, there is little evidence regarding the use of computerised therapies for depression among adolescents. Further, there is little evidence regarding any interventions for depression among adolescents who are in alternative schooling.

Identifying ways to address depression among adolescents in alternative schooling is thus an unexplored area. The weight of evidence suggests that CBT based approaches should be considered. However in the contemporary New Zealand context there was unlikely to be a large new investment in CBT therapists. Prior to beginning this research I became aware of the planned development of a New Zealand cCBT programme. I considered that this might represent an opportunity to address unmet mental health needs of adolescents in alternative schooling. On the basis of contemporaneous evidence one could have hypothesised that cCBT might be effective with this group as rates of depression appeared high and utilisation of mental health services appeared low. Conversely, one might have predicted that such a brief intervention would be ineffective given the extent and complexity of problems faced by many of these young people.

I considered that investigating the potential of cCBT in this group would be of value, as few adolescent cCBT programmes had been tested and none had been tested outside of mainstream high schools or people seeking help from health services. I considered that this would be of interest in terms of supporting adolescents in alternative schooling and would have potential implications for other high needs groups of young people.

**Table 4: Interventions to treat or prevention depression among adolescents in alternative schooling, 1995-2008**

Trial	Stated aims of the research	Study design/description	Sample demographics	Outcome measures	Outcomes
Carpenter-Aeby, T. and V. G. Aeby (2005)	To determine whether an alternative schooling programme improved social functioning and educational achievement for chronically disruptive students, and whether the schooling programme fulfilled its goals.	Uncontrolled pre-post intervention evaluation.  Setting: An alternative school for chronically disruptive students.  Format: individualised psychosocial interventions and educational interventions. Psychosocial interventions were led by a social worker and included cognitive behavioural interventions.  Duration: Average of 24.9 hrs of mental health intervention per student.  Assessment points: Pre and Post intervention (with follow up for educational measures). Time period not specified.	All students assigned to an alternative schooling programme for disciplinary reasons in the USA  N = 599 (students excluded from the study if they did not complete the programme, complete intake and exit interviews or receive mental health services. Number beginning the study not specified).  Ages: 10-22 years  Gender: approx. 75% male  Ethnicity: approx. 80% Afro-American	Birlson Self-Rating Scale for depression  Rosenberg Self-Esteem Scale  Nowicki-Strickland Locus of Control Scale  Life Skills Development Scale–Adolescent form  Grade point average, attendance & post programme school placement	Paired sample t-tests indicated: - a significant drop in depression for 2 out of 5 years (data not presented) - significant improvements in self esteem (all years) - locus of control became more internal in 3 out of 5 years - significant improvements in life skills in years where this was measured.  Achievement and attendance improved but improvements were not maintained when students returned to mainstream education  The education programme fulfilled goals of reducing dropout and removing difficult students from mainstream schools
Wignall, (2006)	Pilot evaluation of modified Adolescents Coping with Emotions (m-ACE) early intervention group	Uncontrolled pre-post intervention evaluation  Setting: 4 special behaviour schools for students excluded from 'normal' secondary school	17 participants selected from 4 sites on the basis of behavioural and depressive symptoms (19 students began the programme, 2 excluded from the study due to	Center for Epidemiological Studies Depression Scale for Children (CES-DC), Youth Self report	Paired t-tests indicated pre to post intervention there were significant drops in: - CES-DC scores - number of participants with clinically significant symptoms of depression - externalising behaviour problems

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<p>CBT programme for special behaviour school students with behaviour problems and depressive symptoms.</p>	<p>due to an extended history of behaviour problems</p> <p>Format: group CBT programme</p> <p>Duration: 11 sessions, total of 10.25 hours</p> <p>Assessment points: Pre and Post intervention. Time period not explicitly stated although whole programme occurs within one school term.</p>	<p>completing less than 9 of the 11 sessions)</p> <p>Mean age: 14.2 years</p> <p>Gender: approx. 76% male</p> <p>Ethnicity: 17.6 % indigenous, no other ethnicity reported although 94.17% born in Australia</p>	<p>Associated measures: Social problem solving inventory –revised; Children’s Automatic thoughts Scale; Bryant Empathy Scale Satisfaction questionnaire</p> <p>Parent and teacher rated Strengths and Difficulties questionnaires</p>	<p>and significant improvements in dysfunctional thoughts; empathy and negative problem-solving orientation</p> <p>High satisfaction</p> <p>Report of using skills, especially anger management, realistic thinking and negotiation</p> <p>Insufficient data to report parent and teacher ratings</p>
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## **Part 4: The development of 'SPARX' cCBT programme for adolescents**

### **The beginnings and my own role**

The development of a New Zealand adolescent specific cCBT programme began with work by Associate Professor Sally Merry, Child and Adolescent Psychiatrist. Following research and work with primary care providers, Dr Merry considered that computerised evidence based programmes, which teenagers could use in primary care and other settings, might help to reduce the impact of depression among young people in New Zealand. However, at the time, there were no publically available, developmentally appropriate programmes (Stasiak 2008). Beginning in 2003, Dr Merry supervised PhD student, Karolina Stasiak, who developed and tested a 2D prototype of such a programme with school students seeking help from school guidance counsellors. This programme, 'The Journey' (Stasiak, 2008), was viewed positively by participants and results were promising, although the need for more engaging computer programming was identified. In 2008, Dr Merry secured funding from the Ministry of Health to develop and test a more sophisticated cCBT programme for depression among adolescents. I was working alongside Dr Merry as part of the Adolescent Health Research Group. In discussion, Dr Merry and I agreed that it was unknown whether such an approach might be effective with young people who had high, complex health needs and whose needs appeared to be poorly met by contemporary mental health services. I began to work with Dr Merry and others to help develop this programme and to help test it with young people seeking help for depression in school guidance and health care settings. My role included drafting, refining and finalising the programme content with Dr Karolina Stasiak, Mathijs Lucassen and Matthew Shepherd, under the supervision of Dr Sally Merry. We enlisted the support of young people, and cultural advisors, expert CBT therapists and a specialist learning technologist. A computer games company, Metia Interactive, worked closely with us to develop the software. This programme became 'SPARX'.

My specific contribution to the development of SPARX included:

- Helping to organise and facilitate youth focus groups and youth workshops, including drafting the focus group questions and helping to integrate youth workshop feedback into an overarching story
- Helping to shape the programme's overall concepts, including the integration of learning and play
- Helping to shape the overall narrative of the game part of the programme, including writing an initial outline of the narrative for several modules

- Helping to translate CBT concepts into metaphors and visual images in the programme, for example providing initial concepts of the 'shield against depression' and the 'Smart Positive And Realistic thoughts that you want to Keep' which became 'SPARX'
- Leading the development of social skills and communication skills components of the programme
- Leading the development of the final module of the programme (this module includes aspects of help seeking, distress tolerance, and motivational aspects of the programme, a programme summary and the climax of the SPARX narrative)
- Helping to shape the emphasis on help-seeking, communication skills and distress tolerance which is included in the programme
- Commenting on and helping to shape other modules particularly the welcome, orientation, psychoeducation and dealing with anger and other strong emotions modules.

In addition to this, I also began my PhD research into the usefulness of such a programme with adolescents in alternative schooling.

## **Programme Aims**

Our aims were to develop a computer programme for mild to moderate depression which was developmentally appropriate for adolescents and was culturally relevant for young people in New Zealand. We wanted the programme to have the potential to increase the accessibility of therapy; hence, the programme was designed to be completed under minimal supervision and to be feasible without high specification computers or advanced information technology skills. We utilised CBT and, based on cultural advice and clinical experience, included an emphasis on tolerance of strong emotions as well as a greater emphasis on interpersonal skills than is often included in CBT programmes. We specifically aimed to promote help seeking and to offer other options for dealing with feeling down for users who might need or prefer these. We aimed to ensure the programme was engaging and appealing and would support young people to utilise skills and learning from the programme in everyday life.

## **Literacy and Computer Literacy**

We wanted the programme to be inclusive of young people who may not have high levels of literacy. Thus, content in SPARX is provided by voice over, as well as appearing on the screen. Secondly, reading was kept to a minimum and simple, direct, active language was used.

The vast majority (94% in 2007), of New Zealand secondary school students have a computer in their home (Adolescent Health Research Group, 2008b); as do the majority (over 70% in 2009) of AE students. The majority of adolescents (65% of school students in 2008 and 75% of AE students in 2009) play computer or electronic games most days (Adolescent Health Research Group, 2008b; personal communication, Adolescent Health Research Group, 2012). However we did not wish to exclude those who were not confident computer users or game players. Thus gaming skills were kept simple and help was available (via the help section of the notebook and via assistance from ‘the Bird of Hope’ where a user did not succeed after multiple attempts at an exercise).

We held workshops and focus groups with diverse groups of adolescents (including students in AE) during the development of the programme, to help to check that literacy and gaming requirements were at an appropriate level.

## Putting therapy onto a computer programme

We wished to translate therapy to a medium that therapies were not designed for. This required identification and analysis of the therapeutic processes that we were trying to achieve and the opportunities afforded via the medium.

CBT has been well articulated. While we wished to utilise tested approaches, we did not want to use a copyrighted system and needed the flexibility to shape the system to our aims and format. Thus we reviewed CBT models for teenagers and identified key elements of CBT which we reviewed with our content development team and our advisors. We also aimed to incorporate important aspects of ‘common elements of therapy’ (see Chapter 3), including components typically offered by the therapist, such as a sense of empathy and support. Once key elements (Table 5) were agreed, we developed detailed plans for the content of each of these components.

**Table 5: Therapeutic elements included in the cCBT programme**

Common Elements of therapy	<ul style="list-style-type: none"> <li>Sense of empathy and support</li> <li>Expression of hope</li> <li>The idea that depression is treatable</li> <li>Homework or practice of skills</li> </ul>
CBT specific skills (knowledge, skills, behaviour)	<ul style="list-style-type: none"> <li>Psychoeducation</li> <li>Relaxation skills</li> <li>Activity scheduling</li> <li>Problem solving</li> <li>Cognitive restructuring</li> <li>Interpersonal skills</li> </ul>
Additional emphases	<ul style="list-style-type: none"> <li>Promotion of help seeking</li> <li>Dealing with strong emotions</li> </ul>

The translation of therapy to computer required some adjustment to fit the medium. Some strategies (such as providing example scenarios) are particularly compatible with computerised formats. Strategies such as goal setting might be utilised in computer or face to face therapy. Perhaps the most challenging aspect for computerisation was the development of a therapeutic relationship. To support the learning of skills and the common elements of therapy we used a bi-centric frame of reference (Salzman, Dede, & Bowen Loftin, 1999). The programme included both first person direct interaction with a warm and supportive character called 'The Guide' and immersion in a 'game world' where users learnt and practiced skills within a fantasy setting (Table 6).

The programme is structured as 7 sequential modules. Each module or level begins with direct interaction with the guide (welcoming the user, checking mood, reviewing progress, giving feedback, suggested further help if required and outlining the purpose of the coming module). This is followed by transition through a portal to the game world, in the form of a personalised avatar, to learn and practice skills through narrative and game features. Users then return to the guide and review learning and set individualised challenges to undertake in real life. Additionally, a notebook is provided which includes summaries of information and space for notes. A virtual copy of the notebook is in the programme and a physical copy of the notebook is given to users. At the outset of the programme the guide explains the use of fantasy and other parts of the programme and invites the user to try it out or take up other options (including accessing GP care or face to face therapy). These alternatives to cCBT are explained and can be returned to throughout the programme.

## **Therapeutic relationship and common elements of therapy**

We aimed to achieve a warm and caring environment, primarily through the guide. The guide was carefully designed in terms of image and approach using feedback from young people and advisors. The words that he utilised were scripted to be therapeutic. The image was designed to be powerful and supportive. We utilised a voice actor who provided a warm and encouraging tone. The guide explicitly expressed ideas that depression was treatable (via SPARX and other methods), expressed the expectation that the user would feel better and encouraged the use of further help seeking.

## **Learning and behaviour change**

Understanding what one is to learn, why it is relevant, and how one is to learn it, is considered to be important for learning (Dillon, 2005). This was provided via the guide using explicit instruction (audio with text subtitles) and interactive graphics on a virtual whiteboard and in the user notebook. The

utilisation of both egocentric (personally embedded) and exocentric (where one has a more external and abstract view of material) frames of reference appears to support the development of both abstract and experiential understandings and hence enhance learning (Salzman, et al., 1999). The use of both the guide and the game world provided this opportunity.

Social learning theory has identified the importance of learning from others, including from credible and likeable characters (Bandura, 1977; Baranowski, Buday, Thompson, & Baranowski, 2008). Opportunities for social learning were provided by the guide and by diverse characters within the game world.

In both the fantasy and guide parts of the programme we used varied learning activities to provide multiple learning opportunities, including activities which required strategising, problem solving and hypothesis testing, to promote higher order thinking.

Visual images, metaphor and mnemonics were used to promote recall; these can also promote understanding of abstract concepts (Klopfer, Osterweil, & Salen, 2009; Salzman, et al., 1999).

Rewards or reinforcement are important for learning and were provided throughout the programme.

Motivation within the game was enhanced by immersion, game play and messages from characters (Dondlinger, 2007). Motivation to continue behaviours outside of the computer programme was supported by experiences of competence and efficacy within the programme, messages of hope, expectations of change and goal setting and goal review (Dondlinger, 2007; Thompson et al., 2010). For example, following each of the game world sessions, the guide encouraged review of the learning from the session, invited the user to identify ways in which they would like to utilise the material and encouraged them to set challenges to practice in their own life.

When the user began a new session, previous learning was reviewed and links were made to new material. These strategies were designed to enhance integration and consolidation of learning (Thompson, et al., 2010), to focus attention and to promote the transfer of skills to new settings (Thompson, et al., 2010).

Computer programmes offer particular opportunities for promoting learning. We used appealing graphics, an overall narrative and opportunities to experience challenge, self determination, competence and social relatedness, in order to gain and maintain users' attention and facilitate an immersive experience (Przybylski, Rigby, & Ryan, 2010). Immersion is thought to facilitate focus, deep learning, motivation and the translation of learning to new settings (Baranowski, et al., 2008; Przybylski, et al., 2010). Narrative that is designed around learning objectives can allow deep affective learning



and the integration of abstract concepts into a range of meaningful, memorable learning experiences (Dondlinger, 2007).

The computer medium allowed us to provide exploratory and graduated naturalistic learning experiences and to provide opportunities to practice skills in an environment which was safe and yet where choices had identifiable effects (Read & Shortell, 2011). For example, users could first address problems in a small way and over a number of sessions test various approaches to dealing with them and develop increasingly complex skills for doing so.

Together, these strategies were designed to promote attention and engagement, to allow the production, testing and practicing of new behaviours and to promote the transfer of learning into everyday life.

## ***The Overall Narrative in SPARX***

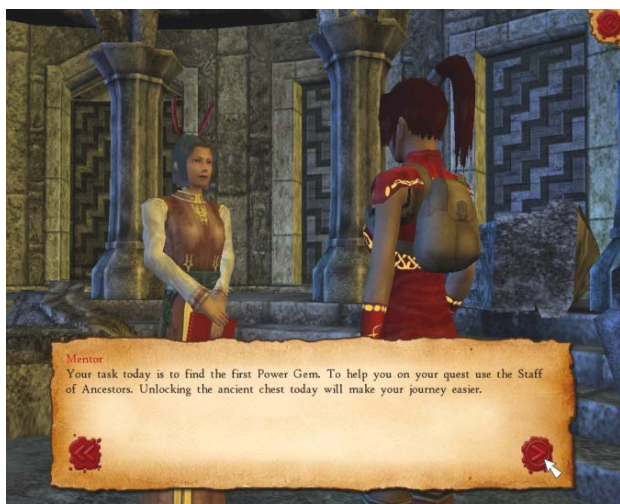
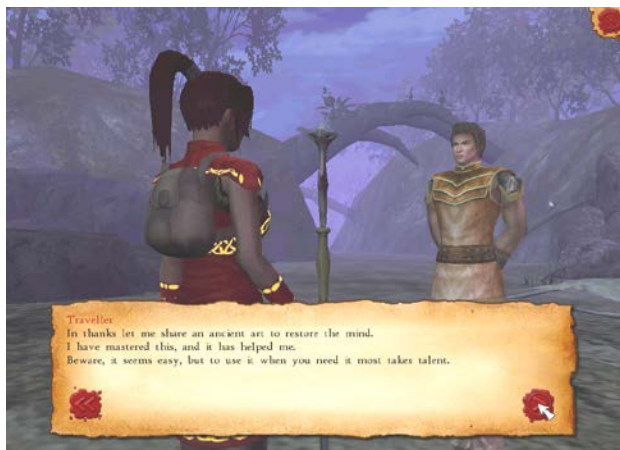
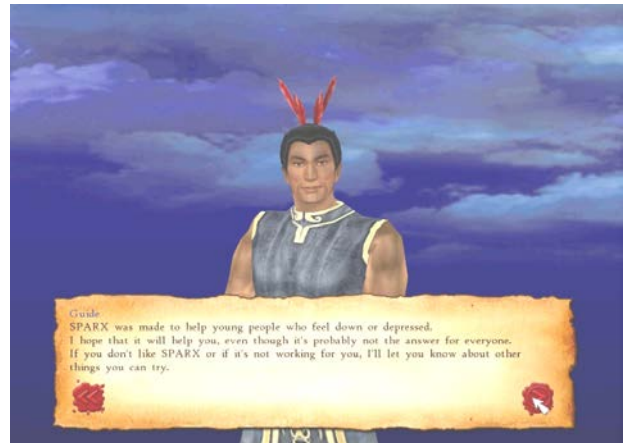
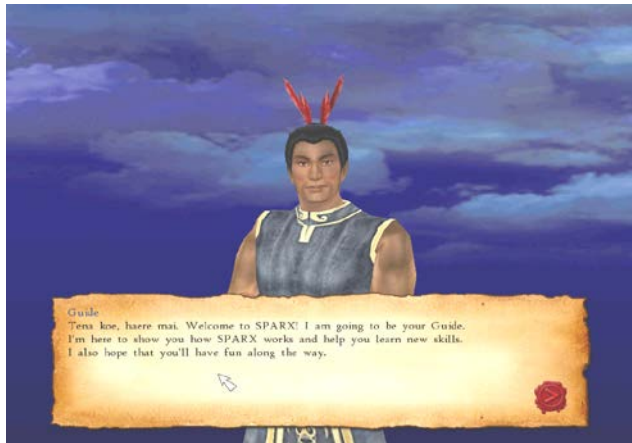
*In ancient times the world was in harmony, with negative and positive energies present and the gems of power forming a sacred circle and holding all in balance. The ancestors wanted to rid the world of negativity and bundled the GNATS into a magical chest contained within the circle. For eons the energies remained imprisoned, slowly growing more powerful until they erupted forth, splitting the circle, sending the power gems out across the earth and spewing negativity forth. Since this time the world has darkened, ice, fire and water have taken hold and people have lived surrounded by negativity and limited by fear, inactivity and doubt.*

*The hero from another world (the user of the programme) is called to right the balance. To do this they must release hope, battle the negative energies, solve problems, gain positive SPARX and find the gems of power. Along the way they assist and learn from characters in the game, use skills from the 'shield against depression' and gather precious items which aid their cause.*

**Table 6: Programme Outline**

<b>Level</b>	<b>Therapeutic content</b>
1	Welcome, rationale, Psychoeducation: depression as a common challenge, depression as modifiable, methods of dealing with depression Linking thoughts, actions and feelings Expression of hope Introducing GNATs (Gloomy Negative Automatic Thoughts) Relaxation skill: controlled breathing
2	Activity Scheduling Interpersonal skills: presenting a confident manner, dealing with feeling socially anxious Introducing the Shield against Depression Relaxation skill: progressive muscle relaxation
3	Dealing with strong emotions: anger and hurt feelings Interpersonal skills: listening skills, assertion and negotiation
4	Problem solving using STEPS (Say the problem, Think of solutions, Examine the pros and cons, Pick one and try it, See what happens) Cognitive restructuring: identifying SPARX (Smart, Positive, Active, Realistic, X-factor thoughts)
5	Cognitive restructuring: identifying GNATS, recognising different types of GNATs
6	Cognitive restructuring: challenging unhelpful thoughts using RAPA (Reality check, Another view, Perspective, Action thinking)
7	Distress tolerance Keeping on trying, asking for help, overcoming barriers to change and options for more help Summary

Figure 1: Screen shots of the SPARX cCBT programme



## Chapter 4: METHODOLOGY

In this chapter I will summarise the rationale for this research and discuss the overall methodology. The method for each study or component of the research is detailed in the individual chapter which reports that study (chapters 5-8); here I provide an overview of why the overall methodology was selected and how the studies fit together.

### Rationale

I have identified that education is an important predictor of health and well-being and that adolescents in alternative schooling face considerable disadvantages, have high rates of health difficulties and face difficulties gaining access to health care. I have identified that adolescence is an important time developmentally, and that while young people are in alternative schooling may be a good opportunity to support them. I have shown that depression is important in this group, and that there are treatments and prevention programmes that are likely to be effective for reducing depression. However, most young people who might benefit from such interventions do not get access to them and this may be particularly the case for adolescents in alternative schooling.

As outlined in chapter 3, cCBT has been shown to be effective for depression among adults and appears to reduce some barriers to evidence based mental health care. It may be effective for the treatment and perhaps the prevention of adolescent depression; however, there was little investigation of its use with teenagers at the time of beginning this research. There was a lack of developmentally appropriate cCBT programmes and there was no research regarding whether cCBT might be of use among adolescents in alternative schooling, educationally alienated young people, or indeed among any groups of young people marginalised from mainstream education and health services. Hence I contributed to the development of a cCBT programme (described in chapter 3) and set out to investigate whether cCBT might be useful for reducing symptoms of depression among adolescents in alternative schooling.

There is no single way of defining whether a health care intervention is 'useful'; however, quality frameworks for health care interventions generally require:

- acceptability: i.e. that users find an intervention acceptable
- effectiveness: i.e. that the intervention has positive impacts on the health issue, and

- achievement of population or system criteria, such as feasibility, efficiency and equity (S. M. Campbell, Roland, & Buetow, 2000; Kaltenthaler, Sutcliffe, et al., 2008; Maxwell, 1992; Seddon, Marshall, Campbell, & Roland, 2001).

For cCBT to be used successfully in alternative schooling would presumably require many factors, such as: alternative schooling providers and/or young people believing that cCBT was needed or beneficial; providers being willing to support its use; parents/guardians being willing to consent to its use; adolescents being willing to try it out and the intervention being satisfactory enough to maintain participation. Secondly, for cCBT to be useful it would need to have a significant impact on symptoms of depression and to be safe. Finally, cCBT would need to be feasible or practicable to implement in alternative schooling.

Thus I developed a series of four studies to:

- explore the attitudes of youth work service providers towards cCBT for depression, their interest in using it and barriers/facilitators to its use, how they would want to use it and what support they would require
- investigate the ways adolescents in alternative schooling currently deal with depression and access help, their interest in computerised therapy and, if they were to use computerised therapy, how they would wish to do so
- test the likely effectiveness of cCBT on symptoms of depression among adolescents in alternative schools in “real world” conditions.
- explore user, parent/caregiver and service provider satisfaction with cCBT for depression, their perception of its impact and suggestions regarding its utilisation.

Broadly speaking, these are acceptability, effectiveness and feasibility criteria.

Given these objectives and the lack of research in the area, both exploratory and hypothesis testing approaches were required. Hence I utilised a pragmatic, mixed methods approach.

## **A pragmatic mixed methods approach**

A pragmatic mixed methods approach utilises a range of methods (typically both qualitative and quantitative methods) (Brannen, 2008), selected to investigate each component of the research question in order to obtain more useful findings than might be provided by any one method alone (Mackenzie & Knipe, 2006; Quinn Patton, 2002). Use of mixed methods is increasingly the norm in the evaluation of social and health interventions (Munro & Bloor, 2010; Palinkas, Horwitz, Chamberlain, Hurlburt, & Landsverk, 2011) and has been supported by the UK Medical Research Council (Munro & Bloor, 2010) and the National Institute of Mental Health and National Institutes of Health in the United

States (Palinkas, et al., 2011). This has been based on the continued emphasis on experimental trials, and on increased interest in consumer and stakeholder perspectives (Palinkas et al., 2011).

The most rigorous way to objectively test the effect of interventions on predetermined outcomes is via randomised controlled trials (RCTs) (Morris, 2006; Oakley et al., 2006); hence, these are critical and are widely used in health care research. However, even if interventions are effective, they are unlikely to be used as designed if consumers and service providers do not consider the interventions needed, appealing, helpful and practicable. Conventional RCTs do not explore these factors (Oakley, et al., 2006). To investigate the use of interventions and the experiences and views of stakeholders, methods such as process evaluations, observation, questionnaires and interviews are appropriate (Morris, 2006; Oakley, et al., 2006). Where little is known about an area, exploratory approaches, which can allow for the generation of new ideas, are particularly appropriate (Creswell & Plano Clark, 2007). Thus, multiple methods are required to understand whether cCBT is acceptable, effective and feasible in alternative schooling.

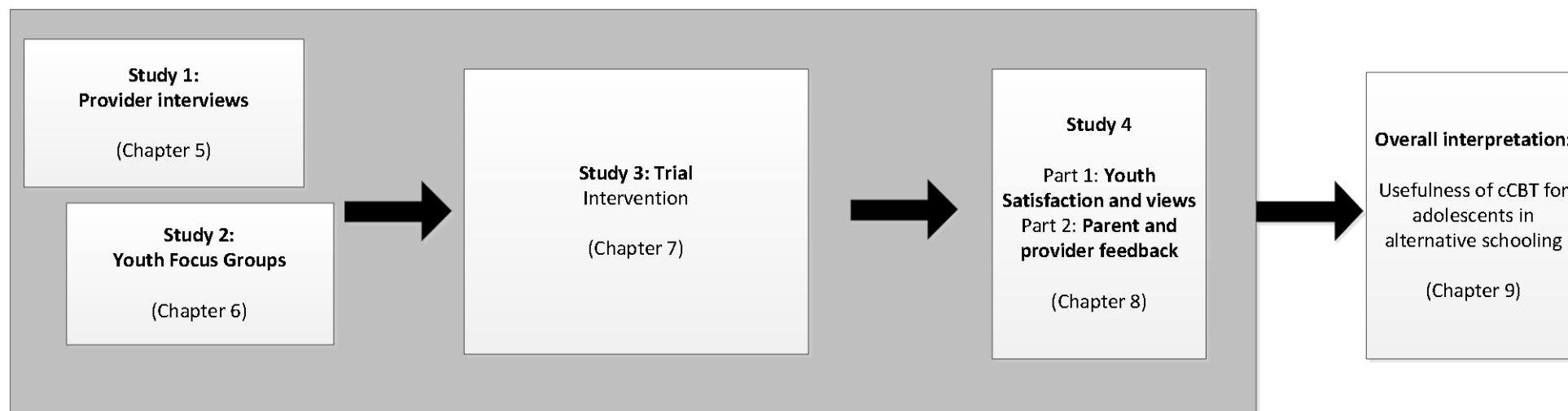
Within mixed methods, the different methods retain their respective strengths, weaknesses and methodological requirements (Quinn Patton, 2002). Efforts must be made to maintain validity of each of the included methods. There are also challenges in integrating findings from different methods (O’Cathain, Murphy, & Nicholl, 2008; Spillane et al., 2010). For example, qualitative approaches typically emphasise rich description, are generally viewed as embedded within the particular circumstances of the study and often emphasise theory building, whereas a trial is usually focused on testing outcomes (Stake, 2010), generalisability is prioritised and the development of theory is seldom a focus (Munro & Bloor, 2010). There are currently no generally agreed guidelines to assess the quality of mixed methods research (O’Cathain, et al., 2008; Palinkas, et al., 2011). However, O’Cathain et al. (2008) proposed that good reporting of a mixed methods study should include specification of: the rationale for the use of mixed methods; the sequence of methods; the purpose, sampling frame and data collection, methods of analysis and limitations of each method; how the findings from the various methods have been integrated and the limitations of the overall approach (O’Cathain et al., 2008). I have utilised these principles in the reporting of this research. Where reporting qualitative data, I have been guided by the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007). Where reporting data from the trial, I have followed the 2010 CONSORT guidelines for reporting randomised trials (Schulz, Altman, & Moher, 2010).

## **Methodology for this research**

The four studies comprising this research and the methods for each are represented in Figure 2. In brief, the first study utilised interviews and focus groups with youth work service providers (including providers of alternative schooling), the second utilised focus groups with adolescents in alternative schooling, the third utilised a pragmatic randomised controlled trial design (Zwarenstein et al., 2008) and the fourth component of the research was based on semi-structured interviews with trial participants, a sample of their parents/caregivers and the alternative schooling providers who had overseen the implementation of cCBT. Chapters 5 to 8 present these studies, including the rationale for each individual study and the methods used.

Using slightly modified terms from Creswell and Plano Clark (2007), this mixed methods approach falls somewhere between ‘using qualitative data within an overall experimental design’ and ‘using both qualitative and quantitative data to understand a problem’. The qualitative data collected prior to the trial was utilised to help answer the specific research questions posed and to shape the methods for the trial. Embedding the trial within research exploring treatment preferences allowed user preferences to inform trial design. As discussed by Donovan et al. (2002) and Oakley et al. (2006), this might have increased recruitment and relevance of findings. It also allowed the research programme to have a participatory element as described by Bagnoli & Clark (2010). The trial was designed to provide evidence of possible effectiveness of the intervention. The final qualitative components were carried out in order to help understand the findings regarding effectiveness, to provide feasibility and acceptability information and to help understand implementation issues. Each component contributed to the overall study of the usefulness of cCBT in alternative schooling. Prior to beginning the research I developed a stakeholder advisory group. This included youth, AE and cultural advisors and kaumatua (cultural) support. This development of connections with communities of interest is highlighted as part of a social work research role by Morris (2006) and is emphasized as culturally appropriate in the framework shared with me by my cultural advisor. Additionally, focus groups and workshops were held as part of the process of developing SPARX as outlined in Chapter 3.

**Figure 2: Overview of the research programme to investigate the usefulness of cCBT for symptoms of depression among adolescents in alternative schools**



**Study 1 & 2:**  
**Procedures:** Semi structured interviews; focus groups  
**Outcomes:** Publications re interest and preferences relating to cCBT (youth and providers); refinement of cCBT programme, trial design and post intervention interviews

**Study 3:**  
**Procedure:** Pragmatic randomised controlled trial, including investigation of changes in symptoms, adherence/ completion of intervention and safety  
**Outcomes:** Publication re likely effectiveness of cCBT in this group

**Study 4:**  
**Procedure:** Semi structured interviews  
**Outcomes:** Publication re youth experience/views of cCBT; chapter re parent and provider feedback

**Procedure:** Interpretation of results of research programme with respect to acceptability, feasibility and probable effectiveness of cCBT for adolescents in alternative schooling  
**Outcomes:** Discussion chapter

Graphic after Cresswell Plano Clark, 2007



## **Focus Groups and Interviews**

Focus groups and semi-structured interviews were selected as means to gather data to inform understandings of youth, parent and provider views and experiences. Each of these methods are mainstays of research when user views are valued; when little prior information exists and where new views on an issue, product or programme are sought (Quinn Patton, 2002). Focus groups allow participants to build on others contributions, can be an efficient method of gathering open ended data from a number of persons, and are generally appropriate for the investigation of social or cultural issues or contexts (Smith & Pitts, 2007). Individual interviews can provide greater assurance of confidentiality than groups, allow the probing of sensitive issues that people might not wish to discuss in front of peers, and are more appropriate for eliciting individual experiences or views (Smith & Pitts, 2007). Hence focus groups were used to investigate youth and provider views regarding the idea of cCBT, while one to one interviews were used to explore personal experiences of it.

Groups and interviews are usually conducted face-to-face. This may enhance rapport building and allow the interpretation of contextual influences and non-verbal cues (Bryman, 2008). However remote interviewing (via telephone or computer) can reduce the research burden on participants and may increase participation rates and enhance quality of data due to the greater experience of anonymity (Bryman, 2008). Here face to face methods were used, except that the views of parents of trial participants were sought by telephone in order to minimise the research burden on parents and maximise rates of participation. Additionally, where follow up interviews of SPARX could not be completed face to face due to participant non-availability, participants were offered alternatives. This pragmatic approach was selected in order to maximise participation and hence reduce possible biases that might be introduced with more selective participation.

## **Analysis of focus group and interview data**

I have used a general inductive approach (Thomas 2006) to analyse findings from focus groups and interviews. As this approach was used in three of the four studies, the rationale for why it was chosen is discussed here.

Inductive analysis begins with specific unique observations and from these identifies common, significant or general patterns, themes, categories or dimensions. Thus, understandings are developed from interpretation of raw data, rather than from testing pre-existing theories or ideas (Dew, 2007; Quinn Patton, 2002; Thomas, 2006). Inductive analysis is useful for describing phenomena, for generating new models or theories, for summarising and displaying data and drawing conclusions regarding evaluation questions (Quinn Patton, 2002).

There are several types of inductive analyses. A 'general inductive approach' was identified by Thomas (2006) to refer to qualitative inductive analyses commonly used in health and social science research, which sought to answer evaluation objectives using models, theories, categories or themes derived from raw data. Other authors have used the term 'conventional content analysis' to describe similar approaches (Hsieh & Shannon, 2005). General inductive analyses share similar starting points with grounded theory, discourse analysis or phenomenological approaches as they too build ideas up from specific observations. However, these latter approaches typically seek to develop theory or in-depth analyses of experiences (Hsieh & Shannon, 2005; Quinn Patton, 2002), while the objective of a general inductive approach is to identify the meanings, themes or categories relevant to the research objectives (Thomas, 2006). Thus, likely outcomes from a general inductive analysis include descriptions or important themes, concept development or initial model building.

A general inductive approach was relevant for the interview and focus group data in my research as I sought to answer specific evaluation questions from raw data. I wished to utilise a systematic approach, which did not pre-suppose or test particular ideas but did have evaluation objectives in mind.

Procedures for assessing trustworthiness in general inductive analyses include peer debriefing, stakeholder checks, research audit processes and consistency checks (Thomas, 2006). Procedures used in this research are described briefly in each of the relevant articles and are summarised in Appendix C.

## **A pragmatic trial**

Study 3 was a randomised controlled trial of immediate, compared to delayed, cCBT among adolescents with depressive symptoms in alternative schooling. Assessments of depressive symptoms and other measures of psychological functioning were made before and after the intervention and at follow up for the immediate treatment group.

The purpose of the trial was to provide an indication of effectiveness of cCBT in this group in real world settings. Thus a pragmatic trial (Thorpe et al., 2009), also known as an effectiveness trial (Rush, 2009), design was used; that is, the trial was designed to investigate the effects of the intervention under conditions approximating the usual conditions in which it might be applied (Rush, 2009; Thorpe, et al., 2009). In contrast, an 'efficacy trial' tests the effects of interventions under very controlled experimental conditions: ideally both participants and researchers are 'blind' to treatment allocation, participants with complex presentations or co-morbidities are typically excluded and the intervention is delivered exactly as specified. This allows for robust conclusions regarding the impact of the intervention on the target condition, although interventions shown to be efficacious in such trials may not be effective in less controlled conditions. As is appropriate in a pragmatic trial

(Thorpe, et al., 2009), flexibility was allowed in the implementation across sites, exclusion criteria were minimised, and prompting of participants to continue with the intervention was kept to brief reminders only.

Effectiveness of cCBT has not been considered in similar groups previously. Thus the sample size was established to be sufficient to allow demonstration of a large effect size (see Chapter 7), but not larger, as it is not ethical to carry out large clinical trials without reasonable indication that results are likely to be promising (N. C. Campbell et al., 2007).

Thus, a small pragmatic trial was appropriate and ethical for an initial investigation of the effectiveness of cCBT for symptoms of depression among adolescents in alternative schools in everyday conditions. However, as with any initial trial, results should be interpreted with caution. Ideally, they should be replicated in larger rigorous trials and compared to findings from other studies as these become available.

The design and findings of this trial for students with symptoms of depression at baseline is reported in Chapter 7.

## **Integrating results**

Analysis for each study was completed and reported separately. Using the terms of Palinkas et al. (2011) and Creswell Plano Clark (2007), this use of mixed methods is both 'complementary', where different methods have been used to answer different questions, and 'developmental', where qualitative findings from studies 1 and 2 were used to refine methods for study 3.

In the discussion section of this thesis the findings from each of these studies are considered together to make conclusions regarding the acceptability, feasibility and potential effectiveness of cCBT among adolescents who are alienated from mainstream education.

## **Summary**

I aimed to investigate whether cCBT might be acceptable, feasible and potentially effective for adolescents in alternative schooling. I developed a mixed methods approach including exploration of providers and young people's interest and attitudes towards depression and cCBT, a pragmatic trial of cCBT, and exploration of young people's, parents' and providers' feedback regarding the use of cCBT.

This choice of methodology, with its emphasis on stakeholder voices as well as experimental findings, is consistent with the post positivist paradigm and social work and youth health principles described in Chapter 1. The findings from each of these studies are reported in the following chapters (5-8) and are integrated in Chapter 9, the discussion.

# **Chapter 5: STUDY 1: YOUTH WORK SERVICE PROVIDERS' ATTITUDES TOWARDS cCBT**

## **Preamble**

The opinions of service providers are important in the development of programmes as they might have particular insights into their clients' needs and be aware of issues that would need to be addressed for programmes to be useful. If they are ambivalent or uncomfortable about programmes or find them difficult to use, they may not support or encourage their use (Aarons and Palinkas, 2007). Thus, considering stakeholder opinions provides an opportunity to support the relevance of programme content and delivery.

I carried out a literature search to identify research regarding providers' attitudes to cCBT in 2008. Search terms are included in Appendix B. Medline, PyschInfo, Embase and Social Work Abstracts databases were searched and a Google search was carried out to ensure relevant papers were not missed. Reference lists of identified papers were searched for relevant previous publications and I checked for more recent citations of identified articles. I found that only the views of mental health professionals had been investigated. No peer reviewed research regarding the attitudes of other providers such as youth workers, teachers or social service providers was identified. The need to explore the perspectives of those who might work closely with adolescents alienated from mainstream education was confirmed and so I carried out semi structured interviews and focus groups with these providers as the first component of my research (Study 1, as represented in Figure 2). This timing meant that in addition to findings being a useful contribution to the research, they could also be utilised to help shape both the programme itself and how it was tested, and important questions that were raised could be further investigated in later components of the research.

This chapter consists of a published article which reports my study of youth work service providers' attitudes towards computerised CBT for adolescents. The article was finalised in early 2012, and includes relevant literature up to this date. This article was accepted for publication in Behavioural and Cognitive Psychotherapy 2<sup>nd</sup> March 2012. Processes used are described briefly in this publication. Further details are provided in Appendix C.

Behavioural and Cognitive Psychotherapy is a mid ranking psychology journal; it has published many recent articles exploring the use of cCBT and was particularly suitable for this and other articles.

# **'Youth Work Service Providers' Attitudes Towards Computerised CBT For Adolescents' (in press) *Behavioural and Cognitive Psychotherapy***

**Theresa Fleming, Sally Merry**

Original Submission: 21.6.11; Revised Submission: 8.1.12; Accepted: 2.3.12; Progress as at 15.5.12: in press

## **Abstract**

**Background:** Attitudes of social service providers towards computerised CBT (cCBT) might affect use of cCBT by their clients and may provide important insights which should be considered in dissemination. There is no literature exploring the attitudes of providers of youth work services towards cCBT despite the likelihood of them having close relationships with young people at high risk of mental ill-health.

**Method:** Focus groups and semi-structured interviews were undertaken with a total of 40 providers (21 youth workers and social service staff providing alternative schooling, justice or other intensive youth work programmes to adolescents, 6 youth service managers, 2 trainers, 5 peer leaders and 6 trainees).

**Results:** Participants considered supporting young people who were distressed to be an important part of their role. They were generally interested in cCBT, especially those who were more mental health oriented and those who saw a cCBT programme in action. Their greatest concerns regarding cCBT related to it possibly displacing human contact, while advantages were seen as its appeal to young people and its potential therapeutic power. They would utilise cCBT in a range of ways, with many wishing to offer it in group settings. Training and resources would be required for them to use cCBT.

**Conclusions:** Many providers of youth work services would like to be involved in the use of cCBT; this might extend the reach of cCBT to vulnerable young people. They would wish to utilise cCBT in ways that fit their current approaches. Providers' opinions need to be considered in the dissemination of cCBT.

*Key words:* Computerised, cognitive behavioural therapy, acceptability, providers, youth workers, third sector.

## **Introduction**

Depression is common among adolescents, with up to 24% of young people experiencing a clinically significant depressive episode by the time they are 18 years old (NHMRC, 1997). Rates are higher

among specific groups, including young people from low socio economic communities (Palpant, Steimnitz, Bornemann, & Hawkins, 2006), those alienated from mainstream education (Denny, Clark, Fleming and Wall, 2004) and those involved with justice services (Townsend et al., 2010). Depression in adolescence predicts future episodes of depression and is associated with increased rates of suicidal behaviour and a range of poor health outcomes (Birmaher, et al., 1996).

The majority of young people who are depressed do not receive evidence based treatments (Zachrisson, et al., 2006). This is a function of both external factors, such as a lack of appropriately trained therapists (I. Marks & Cavanagh, 2009) and internal factors, such as low rates of seeking help from health professionals or indeed from any adults whom they do not know, by young people (Rickwood, et al., 2007). Young people in ethnic minority groups, low socio-economic communities and early school leavers face particular challenges in accessing mental health care (Freudenberg & Ruglis, 2007; Palpant, et al., 2006). Efforts to increase the uptake of evidence based treatments include the development of computerised Cognitive Behavioural Therapy (cCBT) programmes which might help with capacity (requiring fewer trained therapists) and with person centred, internal barriers. For example young people might be able to access cCBT directly via the internet or via persons with whom they have existing relationships.

There is evidence that cCBT can be effective for adults with depression (Andrews, et al., 2010) and emerging evidence that this is also the case for young people (Richardson, et al., 2010). However cCBT programmes provided over the internet have had low completion rates among adults (Waller & Gilbody, 2009). Programmes that include personal encouragement and support (often not by a specialist mental health provider) have generally greater rates of completion (G. Marks, 2007). To promote access to and completion of cCBT among adolescents a range of strategies may be important. For example, cCBT can be offered via Primary Care Providers (Marks et al. 2007) or via schools, as trialed in Australia (O'Kearney, et al., 2009). For young people who are in alternative schooling or intensive youth work programmes, youth workers and other social service staff with whom they work closely could be engaged in providing access to cCBT.

Little is known about the attitudes of social service providers to cCBT. Existing studies include surveys of mental health professionals (MacLeod, Martinez, & Williams, 2009; Richard & Gloster, 2006; Stallard, Richardson, et al., 2010; Whitfield & Williams, 2004) and health professionals (Gun, Titov, & Andrews, 2011). Only one of these studies (Stallard, Richardson, et al., 2010) focused specifically on the use of cCBT with children and adolescents. No studies have investigated attitudes to cCBT among youth workers or non-health social service providers. The attitudes towards cCBT of these workers may differ from those of health clinicians, as many focus on the development of strengths and skills and on providing support (Krueger, 2005) rather than on the diagnosis and treatment of specific disorders. Yet

social services staff do perform a wide array of mental health care roles (P. Mitchell, 2009b) and youth workers and others working in similar settings may have contact with young people who are on the margins of mainstream communities and under-use health services (Rickwood, et al., 2005). For some young people they might be particularly important in facilitating mental health care (Rickwood, et al., 2005). For example, young people in Alternative Education programmes have difficulty accessing health care but are frequently supported by tutors (Clark, et al., 2011; Clark, et al., 2010). Thus youth workers and social service providers may influence teenagers' uptake of cCBT programmes. They could inform young people about cCBT or potentially support them to use it. Additionally they may have important insights and concerns that could help improve cCBT programme content or delivery methods.

This study aimed to investigate attitudes to cCBT among a range of youth work service providers from trainees and youth leaders to service managers. We were interested in providers' attitudes and opinions which might impact on the potential utilisation of cCBT through youth work service providers.

## **Methods**

Because this is a relatively unexplored area focus groups and semi structured interview (where there was just one participant) were used.

### **Participants**

A purposive sample (Quinn Patton, 2002) of providers of youth services in the Auckland region of New Zealand was approached in order to gain views from a range of providers, from early career trainees to experienced sector leaders. The sample included diverse cultural groups and staff from services which focused on: reducing youth re-offending; reducing gang recruitment; youth development (particularly among young people having difficulties in school) and alternative schooling (for young people alienated from mainstream schools). The majority of services were based in high deprivation communities. They were spread throughout the greater Auckland region including central, suburban and rural fringe areas. Eleven of 12 sites formally invited agreed to participate.

Seven focus group and four individual semi structured interviews were held with a total of 40 people (24 male, 16 female) including 18 youth workers or other professionals engaged to work directly with young people in youth services; 3 tutors or teachers in alternative schooling programmes; 6 managers of youth services; 2 youth work trainers or lecturers; 5 peer leaders (young people trained and supported to work voluntarily with youth) and 6 trainees (youth work or social work students).

### **Procedure**

Interviews and groups took place during 2008 and 2009 at the participants' workplace or training course. They took 30-90 minutes and were facilitated by TF (a New Zealand European PhD candidate



and social worker with experience working in youth health services and post graduate experience in carrying out interviews and focus groups in community settings). An interview guide was used (Table 7), and discussion was encouraged. Questions were open ended and were generated to encourage discussion on issues which would be likely to affect possible use or support of cCBT by providers. As is appropriate in inductive focus group research (Quinn Patton, 2002) an iterative process was used where earlier findings refined the interview questions and ideas. Groups took place as a cCBT programme ('SPARX') was being developed by our team; thus earlier groups were introduced to the concept of cCBT and were shown printed images from the prototype of our programme, while later ones were able to try out a level of the programme on a computer. Although some feedback specific to the SPARX programme was gained, the focus of discussion was on cCBT in general and that is what is reported here. Field notes were kept and audio recordings made and transcribed by a professional transcriber.

### **Table 7: Interview Guide**

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#### **Interview questions**

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What do you/your team/service currently do to help young people who are down or depressed? (*Probe for do they see this as part of their role? Do they consider depression among clients common/important among their client group?*)

What do you think about the idea of a computer programme to help teenagers with feeling depressed? (*Probe for likes/dislikes/ideas about clients' potential interest*)

Do you think it might be useful to be able to use a computer programme like this in your service? (*Probe for what they see as benefits/advantages and risks/disadvantages*).

If you were to use a programme like this in your service, how would you want to run it/what would you need?

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#### **Data analysis**

A general inductive approach (Thomas, 2006) was used. I (TF) closely read and re-read transcripts multiple times to consider the meaning in text. Text segments were then identified and clustered into meaningful categories. Within each category statements indicating agreement or divergence of opinions was looked for. While transcripts were read without pre-set theories the research questions (Table 7) were kept in mind and data did follow these broad areas. Thus the general or upper level categories were linked to the research questions. The more specific categories or themes were derived from multiple readings of the transcripts and field notes. Six transcripts were independently reviewed by a research fellow and themes under each research question identified. Final categories were derived after viewing both sets of themes and reviewing raw data. Raw text was coded into relevant categories. Within each category quotations that highlighted or expressed the theme clearly were selected as examples. As this was completed transcripts were re-read multiple times to ensure that coding reflected the raw data accurately. Following peer review the themes were presented more clearly in the text of this article and additional quotes were included.

## **Ethics**

Ethics approval was granted by the University of Auckland Human Subjects Ethics committee. Participants gave their own consent. No inducements were offered.

## **Results**

Findings are presented under each of the four key research questions and within these are grouped into themes, categories or dimensions of responses. Quoted responses are taken directly from the raw text. The disproportionate number of responses from service managers and trainers reflects the imbalance in depth of responses to the questions asked. Tutors or teachers are all labelled as “tutors” and trainers or lecturers as “trainers” in order to protect confidentiality within small occupational groupings.

### **Current responses to young people with depression.**

In terms of how participants currently respond to young people who might be feeling down or depressed, the overarching theme was that “youth services care”. Participants considered that developing close relationships with young people and supporting them if they were feeling down or distressed were important parts of their role. There was no dissent from the idea that youth services and youth workers would in some way respond to the emotional needs of their clients.

I mostly do group work at the moment, but if I was worried about someone of course I would talk with them one on one. (Youth Worker)

If our kids are in trouble, obviously we naturally go to the social worker and see what’s happening there, or the guidance counsellor. (Youth Worker)

[Our agency] is interested in how young people deal with problems, resilience and feelings. How can we help them deal with feelings, not make things worse. (Manager)

However participants varied markedly in how they would do this, and tended to diverge into two categories. These were labelled as “not mental health orientated” and “mental health orientated”. These groups were of roughly equal size. The former generally felt depression was not their focus and they seldom saw it in their clients although occasionally they noted that clients had been distressed or suicidal.

They’re [clients] just being happy. Every now and again you see someone, but you can gradually connect with them. Maybe [name] has, but I don’t think I have come across a case where a young person was really into that area of depression. (Manager)

Mostly we don't focus on whether the kids have depression. They could have – but it's the behaviour, attitude and getting into trouble that are the focus. But depression could be there.  
(Youth Worker)

Often these participants reported that mental health problems were difficult to identify. Some felt young people might hide their depression or occasionally be suicidal without previous indication. These participants generally reported that their approach would be to build a trusting, caring relationship with a distressed young person, whatever the specific problem the young person faced. They reported that if this connection was done well, with someone whom that young person could relate to, the young person would talk with them and feel supported. Participants responding in this way sometimes described referral to mental health or counselling services as an option but generally had seldom used it.

Some we refer, like we, I don't know if we have done. But most of the kids we work with we kind of have a way of connecting, and most of the kids that we work with respond because of our environment. It's a very safe, very open, very family environment, so kids can open up really quickly. (Manager)

You can have someone come in and they will be sad and confused and that... If you have a close bond with them, then they will come and talk to you. They just want to speak to somebody who they trust. (Peer leader)

The second cluster of participants considered depression was common among their client group and described responding to depression, suicidality or other mental ill-health as part of their role. They often had an explicit range of strategies that they might use if a young person was feeling down. These participants were called 'mental health orientated'.

People think youth work equals mentoring, activities etc. But youth workers are more than that. They are the people young people disclose issues to. If the young person is not feeling good... you can't ring the [mental health service] then and there and make an immediate referral. Young people want help at that time. They don't want to go to someone else, later. Youth workers need to be able to deal with their needs. Therapy skills are an important part of that. (Manager)

They (youth workers) are not a counsellor or a therapist, but if they are the first person/the person that the young person talks to, then they will need to have some involvement, skills in recognising, responding to issues and getting help. (Trainer)

This cluster of participants described a range of ways in which they responded to depression within their professional identity and service. These included group programmes, mentoring, psychotherapy, meetings with families, working with counsellors and others. Some of the participants in this group who did not currently offer psychotherapy had plans for training in this area. Although many had referred clients to Child and Adolescent Mental Health Services (CAMHS) they often expressed some sadness or frustration that mental health services had not engaged successfully with their clients or that the young people did not want to be referred there.

There is the (CAMHS) some people go there, though this is not very appealing to young people.  
(Youth Worker)

The final theme identified within this section 'mental health services unappealing for 'our' kids' reflected suggestions from both mental health and less mental health orientated participants that mental health services might not successfully engage young people who were from their communities and cultural groups. In contrast, they considered having close relationships with young people in their own communities to be a strength of youth work services.

They (young people) would rather just talk to someone from the (neighbour)hood (Peer leader)

They (clients) do not fit the norm of what is out there and we are always talking about how difficult it is to get help for your kids... they do not fit the norm of what is out there. (Youth Worker)

(The mental health service) doesn't work for our kids. It might work for kids from (wealthier suburbs) but it doesn't work for our kids. They don't go there. How do we bridge that gap? How do we make it applicable to our kids here. Even (local community service), I still feel they are far removed from the kids who have twisted issues in their lives, from the rough, rugged and raw kids. I feel there is a big hole there. In their ability to connect. (Manager)

### **Attitudes towards computerised programmes to help with depression.**

Participants expressed both overall responses and specific perceived advantages and disadvantages or concerns regarding cCBT. None of the participants were currently utilising cCBT.

### **Overall responses**

Responses to the concept of computer programmes for depression spanned a broad spectrum, from enthusiasm to caution. The participants who were most enthusiastic about the concept were generally those who were 'mental health orientated' and viewed or tried out a module of the SPARX cCBT programme on a computer, rather than simply hearing about it or viewing printed screen shots from the prototype of the SPARX programme. Enthusiastic comments included the following:

It's the bazooka! - I mean in dealing with things it's not a little weapon - little gun or something it's the bazooka – it's big – this could make a real impact. (Manager)

Its ace! (Youth Worker)

Others who viewed the cCBT programme were also positive although not as enthused. The majority of participants fitted into this category. Here are some example responses:

Pretty sweet. I want to keep playing it. Kind of makes you understand key techniques that you already knew. (Youth Worker)

It's better than counselling. (Peer leader)

Unexpected, better quality than expected for a Ministry [of Health supported] game. (Trainee)

Other participants thought the programme would be useful for some clients: particularly for boys, those who are 'into technology', those who are less likely to talk, or those who do not use mental health services.

I have dealt with a number of students this year who might benefit from this. They wouldn't go to [mental health service] but would do something. They are into computers. (Tutor)

Be good for young people who don't have the words for what they are feeling. (Youth Worker)

Several people considered that it might be a useful step before engaging in one to one therapy.

Boys don't have the language to talk about what's going on. If the model gives them the language then they will use it. You need to give them the language base. Once that's created you can have the conversations. (Manager)

Finally a minority of participants were cautious about the programme. This included some peer leaders who thought it was better to talk to someone than to use cCBT. However, all the peer leaders agreed that cCBT would be considerably more appealing than talking to a stranger about feelings and that teenagers should be offered a range of options for dealing with depression.

Some people... they don't have the words. But, for some others, if people love you, they just want to speak to somebody who they trust... People have their own style, but for me, I'd rather talk. (Peer leader)

Others were classified as 'cautious' as they focused on questions that they would wish to see addressed such as ensuring safety or having support for cCBT. These concerns are included in following sections.

### **Likes and dislikes or concerns about computerised therapy**

Participants expressed a range of likes and dislikes about cCBT. The most frequently identified advantage was the potential appeal or ability of cCBT to engage young people, and thus operate as a form of gateway to getting help. That is that young people might be open to utilising cCBT and through this to become be more willing or able to talk with their youth service provider.

It's hard to get them to talk, sometimes people just shut down completely, but this might put them in a position where they can talk. (Youth Worker)

I think this is a good tool, especially if you just met somebody. It's better to do this than just straight away say 'oh why are you feeling down?' and stuff like that. And it's good because they get stuff from here and then probably go on to the next level, by meeting each other face to face. This could be like a starting, then you could elaborate. (Peer leader)

The second advantage related to ideas about the potential power of cCBT as a therapeutic tool to create change.

I think it's a great idea – it's potentially transformative for young people. The youth worker has a good relationship – and sees the young person, but this could help shift things, be part of a transformative process. Youth workers can feel quite under resourced. This can help them have access to good skills. (Trainer)

For us depression is just a huge topic and something I know for us can be quite hard. Unless it's at the point of suicide there is not a lot that is available to us about how to help them. You sort of think to yourself, I wish I'd picked that up or I wish I'd known more about what to do and this is where something like this could help. It could really be a help for our kids. (Youth Worker)

It even changes the way you are thinking as you go through. (Youth Worker)

The participants who were particularly enthused or positive about the programme tended to report both these advantages. However the majority of participants focused on the former (cCBT as engaging and facilitating access to help).

Thirdly there were specific elements of cCBT that were thought to be appealing to young people. These included the use of computers; the young person not having to talk with a stranger; and the young person having a higher level of control than they might experience in therapy.

You have to let the kids drive practice, what you focus on – they are interested in computers so we have let this be our way in.... they don't want to read, not so into talking maybe. (Youth worker)

Anything that is web-based for young people, the more the better, because young people love being able to do things in their own time and their own way. (Tutor)

In terms of disadvantages, the most frequently expressed concerns centered on whether cCBT might displace personal contact. Some participants were concerned that this might reduce their role and a few were adamant that cCBT should be used with youth work support and not as a standalone intervention.

I wonder about the byproduct. What's to gain from putting them in front of a screen and what's lost? What about the human contact and that. (Youth Worker)

The work we do is through relationships, we are human beings. (Youth Worker)

I hope it doesn't come to a place where it replaces us! (Youth Worker)

My staff are awesome. You could have it as a tool, not a 'referral.' (Manager)

The second major area of concern expressed by several participants was client safety and the need to be assured that cCBT would not increase clinical risk.

Safety, with anything they do safety is paramount. The staff need to know what's doing. Young people need to feel safe. [However] I think there is potential there. (Manager)

You would need a say in who got to use it and where etc, so it didn't cause more harm. (Youth Worker)

Thirdly, participants occasionally voiced the concern that cCBT might not appeal to all young people, especially those who were very distressed.

They might open up more with a physical game like chucking the ball around than they would with this. (Trainee)

It might come across as patronising, if I'm depressed, [if I've] asked you for help. (Youth Worker)

### **Utility of computerised therapy in Youth Services**

In general participants said it would be useful to use cCBT in services that they worked in. Responses varied from highly enthusiastic to those who were cautious and highlighted training needs or needs for controlled use of cCBT (see next section). Participants' interest in using computerised therapy did not appear to be related to role, training, age or ethnicity. However, in general those who were more 'mental health orientated' and were generally positive about computerised therapy were most interested in using cCBT.

We want to run it here, can we have the exclusive? (Manager)

It could be a great tool for youth workers...so that they can get on with what they are good at and offer support to young people. (Manager)

[We/I] wouldn't just put young people onto the programme without knowing what they were getting themselves into. (Manager)

No participants said that they would not consider using cCBT or that there was no role for such an approach in their service.

### **How participants might wish to use cCBT**

Participants had various ideas about how they might want to use cCBT. While cCBT was presented in focus groups and interviews [by TF] as a possible tool for young people with depression, several groups of participants suggested it should be offered to all the young people in their programmes. This approach was suggested for several reasons. Firstly, it was described as consistent with youth work practices of offering interventions to whole groups of young people rather than identifying individuals with pathology. Secondly, offering the intervention to all young people might reduce embarrassment for distressed young people. Thirdly, a whole group approach would mean that young people who need the intervention are not missed. This could otherwise be problematic, as clients might have unrecognised depression and might not seek help and personnel might not identify those who are distressed.

I work in a youth development model, strengths based, groups... I would avoid labelling, the whole embarrassment thing, offer it to the whole group. The whole group could benefit. (Youth Worker)

You would need to get everyone to do it otherwise the right ones, those with depression, wouldn't get access to it. If you put everybody on it if they are keen to continue they can and if they don't need it they might drop out and that's okay. (Tutor)

Some suggested that a cCBT programme should be supported by someone to lead it and manage risk.

Something like that would be quite a non direct way to address issues and they might feel a bit better about sharing stuff if it was through something like that rather than dealing directly with the person. As long as there is contact with the person as well to kind of drive it and make sure they are safe and whatever, I think it would be quite good. (Tutor)

Participants had diverging opinions regarding how controlled access to cCBT should be. Some respondents thought cCBT should be made available so that young people could access it without needing to go through another person; others considered that access should be managed by someone such as themselves.



It would be good to have a tool; anything that is helpful is good. It would be good to put it on the library computers, then [young people] can access it through the library. (Trainer)

Yes. Yes. [I would use something like this] as a resource for youth workers etc to supply with discretion to who they know could use it. Only if I could have a say in who got to use it and where etc. so it didn't cause more harm. (Youth Worker)

It is key to have somebody to talk through a lot of the stuff with too and maybe to explain if they have any further questions. (Youth Worker)

Participants identified a range of needs for themselves if they were to support a cCBT programme. Foremost among these was training and the opportunity to become familiar with the programme, the evidence behind the programme and how safety would be ensured.

Youth Workers would need to know what it was about, believe in it, have tried it. (Trainer)

Some Youth Workers are very isolated. You would need to make sure they were trained and connected, so if the young person wanted to talk to them then they can respond and refer. (Trainer)

You'd need to do training and you need follow up training. Have an update day every year and have back up for when you get stuck. (Tutor)

For some services limited space and computers would be a barrier. Finally, appropriate information for young people to take home to parents would be required.

The computer issue is a bit of a barrier. We don't really have any computers, just our work computers, none specially for this. (Youth Worker)

Where could we put them [computers] if we had some? Maybe in the corner of the room. (Youth Worker)

## **Discussion**

The aim of this study was to investigate the attitudes of providers of youth work services to cCBT. It is the first study of attitudes to cCBT among providers outside of health and therapy fields. This was considered important as many youth service providers have close relationships with young people who have unmet mental health needs. Our analysis indicated that youth work service providers are interested in supporting the emotional needs of their clients and many are interested in using cCBT.

They would wish to use it in a range of ways including with groups of young people, and they identified needs for training and resources to be able to utilise it.

Youth work service providers regard building relationships with young people as a particular strength of their role and consider supporting young people when they are distressed an important part of what they do. Some explicitly consider the mental health needs of their clients and have specific responses to depression, while others do not. Most would respond to clients who were distressed or depressed by extending their existing caring relationships with young people (providing more caring, or specific psychotherapeutic attention). Youth work service providers are concerned that mental health services may not successfully engage with their clients. There are few other studies in this area, although Mitchell (2009a) found non-medical health and social services personnel provided considerable mental health care. They preferred supportive, understanding roles over identifying pathology and offering illness specific referral or treatment (P. Mitchell, 2009a, 2009b). This is consistent with the preferences expressed here. Participants in this study described offering increased support in response to distress in young people in their services, without necessarily referring elsewhere or formally identifying disorder.

Our finding that youth work service providers are interested in the idea of computerised therapy for depression is consistent with studies of health providers and therapists in Australia (Gun, et al., 2011) and the UK (Stallard, Richardson, et al., 2010; Williams & Martinez, 2008). The providers who were most positive about cCBT were those who more actively considered the mental health needs of their clients, and who saw a prototype cCBT programme. Providers' perceptions of their clients' needs has previously been identified as significant in whether evidence based interventions are implemented (P. Mitchell, 2011). The significance of how programmes are presented should also be considered. Our finding that exposure to a computerised intervention increased acceptability is in line with a previous study which reported higher interest in cCBT among those who saw a demonstration programme than those who only heard about it (N. Mitchell & Gordon, 2007).

The concerns expressed by some participants about cCBT potentially displacing contact with helping professionals and about ensuring client safety are similar to concerns expressed in surveys of therapists and health providers (Gun, et al., 2011; MacLeod, et al., 2009; Stallard, Richardson, et al., 2010). However, whether cCBT does in fact reduce the uptake of personal support has not been established. Additionally, people who work as therapists or youth workers may place a higher value on face to face professional support than the general public do. Indeed several studies have found the public to be more positive about cCBT than therapists are (Waller & Gilbody, 2009). Questions regarding the management of client safety while clients are using cCBT may be addressed through screening and monitoring processes. Whether these processes would be sufficient to assure safety and be reassuring to helping professionals remains to be seen.

Participants in this study had diverse opinions about how cCBT might be best offered within youth services. Some would consider offering it to individuals who were distressed; however, many suggested offering cCBT to whole groups of young people in youth work programmes. Universal use of the 'MoodGYM' cCBT programme in two schools did not show strong results (O'Kearney, et al., 2006; O'Kearney, et al., 2009). However, the use of depression treatment programmes in groups with increased risk is likely to be more promising than universal, unselected approaches (Horowitz & Garber, 2006). Given the high rates of depression and challenges in providing mental health services to young people in intensive youth work programmes such as alternative education and justice settings such an approach should be investigated.

Some providers would wish to have an external provider to lead and oversee safety of clients on a programme offered in this way; others considered that they would do this themselves. Providers also diverged on whether they considered cCBT should be made available for young people to access on their own or whether access should be facilitated through providers such as themselves. Mental health professionals have strongly preferred the latter (Stallard et al., 2010) and completion of cCBT programmes without personal support is low (Waller & Gilbody, 2009). However, an oft cited strength of cCBT is that it might increase treatment for those who are depressed but not utilising helping professionals.

Participants in this study identified that to use cCBT they would need training to ensure familiarity with the programme/s, understanding of the evidence for the programmes and confidence with how safety issues would be managed. Stallard et al. (2010) and others have identified similar training needs to support the utilisation of cCBT by therapists.

Additionally for some youth services, access to computers and private spaces are limited and could limit the utilisation of cCBT.

### **Strengths and limitations**

The most significant limitation is that this is a small study of a specific population; therefore the generalisability is limited. Secondly, TF who carried out the interviews was involved in the development of the SPARX cCBT programme and participants were aware of this. Although full and frank discussion was encouraged, this may have led to a social desirability bias. Thirdly, although participants were asked their opinions of cCBT, they were exposed to one specific cCBT programme ('SPARX'). Computerised CBT programmes vary widely in their content and presentation. Participants' responses may have been different had they been shown a different example. However, this is the first research on attitudes to cCBT outside of health or therapy staff, the second that is youth specific and one of few outside of the UK or USA. It involved a range of providers from managers to trainees from diverse

practice settings. As such, it is a useful exploratory analysis of attitudes of providers of alternative education and intensive youth work programmes.

### **Implications**

Youth work service providers were interested in utilising cCBT. Some thought that offering this tool, with the support of personnel who have unique skills in building relationships with disaffected young people, might be transformative for clients. Many thought that cCBT would be appealing to young people and might facilitate access to further personal support. The interest expressed here suggests that youth services offer a promising avenue for extending the availability of cCBT to young people.

Previous studies have shown that cCBT can be effectively facilitated by non mental health specialists (Cavanagh, Seccombe, & Lidbetter, 2011; Farrand, Confue, Byng, & Shaw, 2009; Williams & Martinez, 2008). Although mental health services backup should be available, the skills required to facilitate the use and completion of cCBT programmes appear to be engagement and support (Williams & Martinez, 2008). The UK National Institute for Health and Clinical Excellence (NICE) guidelines for adults with depression (National Institute for Health and Clinical Excellence, 2009) recommend that the use of cCBT programmes should be monitored and supported by a trained practitioner. Youth service providers may be well placed to facilitate access to cCBT for some young people, either with the support of trained practitioners, or perhaps, with appropriate support, by becoming trained practitioners themselves.

Whether this interest in cCBT might translate into its utilisation in youth services is far from certain. New interventions are seldom adopted on the basis of evidence (Aarons, Wells, Zagursky, Fettes, & Palinkas, 2009), or even interest (Stallard et al., 2010) alone. Rather, there are multiple critical factors; among providers these include their attitudes to the intervention, its compatibility with existing values and approaches, their assessment of client needs, and the availability of resources (Aarons & Palinkas, 2007; P. Mitchell, 2011). We have found positive attitudes towards cCBT as well as some caution. Providers' existing approaches were based on personal supportive relationships with young people; whether cCBT is seen as a tool or a threat to these approaches is likely to be important. Further, utilisation of cCBT in this sector is likely to be promoted by providers' awareness of unmet mental health needs among clients, their exposure to cCBT, and access to resources such as training and computers.

### **Summary**

Youth work service providers are interested in utilising cCBT. This offers a promising avenue for extending the availability of CBT to vulnerable young people if questions of support and safety can be appropriately addressed. How providers would wish to do this needs to be considered. The current findings suggest they prefer to do this in the context of their own caring relationships with young

people without labelling or referring on, and that some would prefer to offer this with groups rather than individually. Resources including training and support would be required.

Non mental health specialist providers can have an important role in extending the use of cCBT; their opinions need to be considered in cCBT dissemination strategies.

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## Chapter 6: STUDY 2: THE VIEWS OF ADOLESCENTS

### Preamble

The opinions of young people are critical to ensuring that programmes for them are appropriate and meet their needs and preferences. If users do not consider a programme to be helpful or appealing in some way they are not likely to willingly utilise it (Kaltenthaler, Sutcliffe, et al., 2008). Considering the target group's needs, wants, priorities and preferences provides opportunities to develop appealing and appropriate programme content and delivery processes (Doherty, Coyle, & Matthews, 2010; Dondlinger, 2007; Kaltenthaler, Sutcliffe, et al., 2008).

I carried out a literature search in 2008 which identified no research regarding the preferences or needs of young people in alternative schooling regarding cCBT or other depression interventions.

I therefore planned Study 2 (see Figure 2) to explore the need for depression interventions from the perspective of the target group, their interest in cCBT, and issues that might impact on how cCBT or other depression interventions should be provided for them. Focus groups were selected as an appropriate method as there was a lack of prior research and as focus groups can allow the development of insights as participants build on others' contributions (Quinn Patton, 2002). Because views that do not accord with those expressed by most participants can be minimised in focus groups (Quinn Patton, 2002), I also utilised brief written questionnaires, completed at the end of focus groups, to allow students to give feedback that they might not have shared in the group. This also allowed the quantification of numbers of students who would want to use cCBT if they were feeling down.

I began this study after beginning the provider focus groups (Study 1) and as we were finalising the SPARX programme. This timing meant that information from young people could help to shape how the programme was tested and themes identified in these groups could be explored further in post intervention interviews (Study 4). Had there been early feedback that the SPARX programme was inadequate, adjustments could have been made. Note that youth workshops and focus groups specifically regarding programme content had been held earlier in the development of the SPARX programme. However, these were not part of my PhD research.

This chapter consists of a published article which reports the study. Further details regarding processes used are included in Appendix C. The article, including literature review and discussion, was finalised late in 2011. *Advances in Mental Health* was selected as an appropriate journal as it has a strong focus on consumer voices and on clinically relevant research in order to promote mental health and to reduce disparities.

# **'It's mean!' The views of young people alienated from mainstream education on depression, help seeking and computerised therapy.'** **(2012) *Advances in Mental Health***

**Theresa Fleming, Robyn Dixon, Sally Merry**

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## **Abstract**

**Background:** Adolescents alienated from mainstream education before they reach the minimum school leaving age have high rates of depression and seldom receive evidence-based mental health treatment. We set out to investigate their views on depression, help seeking and computerised therapy. **Method:** Focus groups with 39 young people (74% males, 49% Maori, 38% Pacific Island, all aged 13-16 years) in alternative schooling programmes for students excluded or alienated from mainstream education. **Findings:** Participants generally thought that depression was real and that people their age suffered from it. The main responses to feeling depressed were self harm, fighting and substance use. Most were very reluctant to talk to health providers about depression. Some would be distressed or might hurt themselves if referred to mental health services. There was a high level of interest in computer programmes to assist with depression irrespective of the gender or ethnicity of the students or whether they felt down in the past. Barriers to using computerised therapies included lack of help seeking, potential embarrassment and access to computers. **Conclusions:** Approaches that allow young people to receive help, without having to actively seek assistance from health professionals may be needed to address depression among this vulnerable group. The use of computer programmes that are appealing and can be provided in non-stigmatising ways appears to be one promising approach.

**Key words:** depression, adolescent, computer based therapy, attitudes, alternative education, New Zealand

## **Introduction**

Young people who leave school early typically have poorer health and economic outcomes than their peers who complete high school (Denny, Clark, & Watson, 2004; Freudenberg & Ruglis, 2007). In New Zealand, Alternative Education (AE) units and other alternative schooling programmes such as youth

wrap-around services, have been set up for teenagers who have been excluded or alienated from mainstream high schools and might otherwise 'drop out' of education. Similar programmes exist in Australia, the USA, England and elsewhere.

Students at AE have approximately double the rates of depression of their peers in high school (Denny, Clark, & Watson, 2004) as well as elevated rates of substance use, unplanned pregnancy, exposure to violence and being in trouble with police (Clark, et al., 2010; Denny, Clark, & Watson, 2004; Grunbaum, et al., 2001). In New Zealand they are more likely to be Maori or Pacific Island students, male and from socio-economically deprived communities (Clark et al., 2010). Despite their higher needs, they report more difficulty in getting health care and help for emotional difficulties than their peers in mainstream education (Clark et al., 2010). However, students in AE also frequently describe feeling re-engaged in learning, cared for by tutors and wanting to make positive changes in their lives since attending AE (Brooking, et al., 2009; Clark, et al., 2010; Smith, et al., 2007).

Depression is predictive of future difficulties including suicidal behaviour (Birmaher, et al., 1996), and may exacerbate and make it harder for students to address other issues such as academic achievement and substance use. Depression is also identifiable and evidence based treatments for depression do exist. In particular, there is evidence for the effectiveness of cognitive behaviour therapy (CBT) (Harrington, Whittaker, Shoebridge, & Campbell, 1998) and emerging evidence for the effectiveness of computerised cognitive behavioural therapy (c-CBT) for depression among young people (Richardson, et al., 2010).

However neither CBT nor c-CBT for depression have been tested among adolescents who are alienated from mainstream education. Additionally access to evidence based treatments for depression typically require the individual or those around them to: recognise that their mood is low or that they have a problem; seek help; find or accept and utilise health service based treatment (Gulliver, Griffiths, & Christensen, 2010; Rickwood, et al., 2007; Zwaanswijk, et al., 2003). These are no small requirements. Familiarity with 'depression' as a mental health issue is mixed among young people, with lower rates of recognition of symptoms of depression among younger adolescents and males (Wright & Jorm, 2009). Depression may be particularly poorly recognised by both adolescents and the adults around them where young people have multiple problems, where an alternative label has 'got in first', or where high levels of distress are normative (Cauce et al., 2002; Watson, Kelly, & Vidalon, 2009). Secondly, particularly for males and adolescents from ethnic minority groups, initial responses to depression seldom include seeking professional treatment (Rickwood, et al., 2007). Thirdly, where young people do seek help from others, multiple studies around the world have found this is more likely to be from friends or family than from health professionals (Barker, 2006; Gulliver, et al., 2010). Finally, depression

has been found to be mildly negating of help seeking, i.e. young people who are depressed may be less likely to seek help (Wilson, et al., 2007).

Although rates of depression are known to be high and access to quality mental health care is likely to be difficult among young people alienated from mainstream education, there has been no research investigating promising approaches to reducing depression with this group.

This study was developed to contribute to understanding the needs and preferences for depression interventions among young people alienated from mainstream education and to consider their views on computerised interventions and cCBT in particular. The study took place alongside a larger project to develop and test a cCBT programme called 'SPARX' for depression among teenagers ([www.sparx.org.nz](http://www.sparx.org.nz)).

## **Methods**

### **Study design**

Little is known about the attitudes of young people alienated from mainstream education towards depression and intervention, therefore a focus group methodology using a semi structured interview schedule was utilised. This method allows the exploration of pre-defined questions with the flexibility for potentially new or unexpected ideas to be considered (Quinn Patton, 2002). The consolidated criteria for reporting qualitative research (COREQ) (Tong, et al., 2007) has been used to guide reporting here in order to allow the reader to consider the credibility of methods used and the trustworthiness of interpretations (these are key issues of quality in qualitative research) (Fossey, Harvey, Mcdermott, & Davidson, 2002).

### **Sample**

Using a purposive sampling strategy, five providers of AE Services<sup>1</sup> and one provider of an education wraparound programme<sup>2</sup> from diverse communities in Auckland were invited to participate. One AE provider did not respond, all other services agreed to hold focus groups. At three sites the class was split into two groups. A total of eight groups were held.

All young people attending the programme on the day of the focus group were invited to participate. One student declined to participate (no reason given) and no students withdrew. There were a total of

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<sup>1</sup> The criteria for being placed in AE in New Zealand include that the young person is aged 13 to 15 years; has been out of school for two terms or more; has been excluded from multiple schools; has a history of dropping out of mainstream schooling after being reintegrated, or has dropped out of the Correspondence School after enrolment as an 'At Risk Student' (O'Brien, et al., 2001).

<sup>2</sup> The wraparound programme is for secondary school students under 16 years, who have been temporarily excluded from school and are at risk of permanent exclusion.

39 participants. Participants reported their own demographic characteristics (Table 8) including ethnicity. Where young people reported more than one ethnic group they were categorised into Maori, Pacific Island, New Zealand European or other using the New Zealand Census Ethnicity Prioritisation Method (Ministry of Health, 2004).

**Table 8: Participant Demographics**

Group	N	Gender		Age in years				Ethnicity			
		Male	Female	13	14	15	16	Maori	Pacific Island	NZE*	Other
1	4	4	-		1	3		1	3		
2	6	3	3			4	2	3	2	1	
3	4	-	4		3	1		2		2	
4	6	6	-		2	3	1	3	3		
5	3	-	3			3		3			
6	8	8	-	1	2	4	1	1	7		
7	2	2	-		2			1		1	
8	6	6	-	2		3	1	5			1
Total	39	29	10	3	10	21	5	19	15	4	1

\* NZE = New Zealand European

### Procedure

Ethics approval was obtained from the University of Auckland Human Participants Ethics Committee (reference no 2008/078). Providers were approached and gave assent for young people in their service to be invited to participate. On the day of the focus groups the study was outlined to all young people present, confidentiality and purpose of the project was explained and all were invited to take part. Young people gave their own written consent and were offered a \$20 gift voucher as thanks for their participation at the end of the group.

A schedule of open ended questions was used to guide the group discussion (Table 9). Reflective and summative statements were used to check understandings of what was said in each group. In all but one group (of 8 people) a level of the SPARX c-CBT programme was shown and young people individually completed a one page questionnaire which included opportunities to comment on the programme and make any additional comments not discussed in the group. As part of this questionnaire participants were asked "Have you ever suffered from feeling down or low for more than

a few days in a row?” (Yes/No), and “If you were feeling down, would you like be able to use a programme like this?” (Yes/No).

All groups took place at the AE or wraparound service. Groups took from 30-60 minutes. All groups were facilitated or co-facilitated by TF (PhD candidate with a clinical experience in youth health and youth mental health services) and five were co-facilitated by a tutor from the young people’s programme or a research fellow. Groups were audio recorded and field notes kept. Preliminary analysis was undertaken after each focus group, once no new information was emerging no further focus groups were held.

**Table 9: Questions used to guide focus group discussion**

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**Interview questions**

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What do you think about ‘depression’? Do you see people around you with depression? Do you think people your age get depression?

How do people your age, in courses like this, cope with depression?

Do they ever ask for help? Do they talk with someone?

What do you think about a computer programme to help people with feeling depressed? What do you think is good/ not so good about having a computer programme like this? Do you think a doing a computer programme for depression would put people off talking to someone/asking for help?

What would put you off using a computer programme like this? What would be needed to make it work/easy to use for students in courses like this?

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**Analysis**

Audio recordings of focus groups were transcribed by a professional transcriber and were checked against the recordings and forwarded to co-facilitators for their review. I (TF) used a general inductive approach (Thomas, 2006) to analyse the data. I read the transcripts closely multiple times to consider the meaning and themes in the text, to allow any unexpected themes to be identified and to derive initial categories that related to research questions.

Transcripts from 5 focus groups were reviewed by a research assistant who independently derived the same initial themes. I reviewed the transcripts from focus groups comprising mostly Maori and/or Pacific young people with Maori and Pacific clinicians/researchers to help ensure issues of cultural relevance were not overlooked. Next I coded meaningful sections of text systematically and looked for key findings in the data. I looked for commonalities and divergence across focus groups. Approximately 10% of coding was reviewed with a research assistant. A high level of consistency in coding was reached.

Data from the written feedback sheets given at the end of focus groups were summarised and frequencies presented; however no statistical testing was planned due the small sample size.

## Findings

The themes from the analysis are summarised in this section, with quotes from the raw data in italics and labelled with (M) for male or (F) for female and with the focus group number to indicate the origin of each quote.

### **'Depression' is a concept that participants are familiar with and see around them.**

Participants in focus groups thought that depression was real, there were no suggestions that depression was an odd or foreign concept or that it did not apply to teenagers, to their own cultural groups or to themselves. Many students had seen people who they thought suffered from depression and generally students thought that depression was common among people their age. Many participants thought that young people often hide depression from others, even those close to them.

*My aunty – sad, lonely, locked up in her room. (F, group 5)*

*Even I get depression. (M, group 4)*

*Some people keep it a secret... (M, group 7)*

Several participants reported that young people might not recognise that they were depressed, not because they were not down, but because this might be normal to them.

*They get down but they like get used to it and then they don't notice cause they are like – get used to it. (F, group 3)*

### **Dealing with depression**

When the participants were asked how young people coped with feeling depressed, in all groups the first and most common response was that they would commit suicide, or would harm themselves or others. Students did not identify any downsides or problems related to these ways of coping, rather they presented these responses in a matter of fact way, as ordinary ways of coping. There were no suggestions of problem solving or trying to change a difficult situation and very few responses which included the involvement of others.

*Yes [I have seen people my age have depression] and they commit suicide. (M, group 4)*

*Self harm. (F, group 5)*

*Kill themselves. (M, group 7)*

*I used to hurt myself... (M, group 7)*

Several groups identified being violent towards others or committing crimes as how young people cope with being depressed. This was particularly common in the boys groups.

They get angry and lash out or take it out on people. (F, group 5)

[They cope by] Being cruel. (M, group 6)

Fists! (M, group 1)

Violence, mischief. (M, group 6)

They do crime... When I get angry and depressed and stuff I ... (do bad stuff?) Yes. (M, group 8)

A second dominant theme was alcohol and drug use. Participants discussed this openly as one of their own ways of coping. This theme was consistent across all the groups.

Take a hit from the bong. (M, group 6)

Do drugs 'n' stuff. (M, group 7)

Have a scull. (F, group 3)

Other methods of responding to depression were avoidant or distraction behaviours and withdrawal including sleeping or trying to ignore it. Having sex was mentioned by both boys and girls as a coping strategy among girls.

I walk off and never come back. (M, group 6)

Try and shut out the daylight, so ... just go back to bed and don't deal with it. (M, group 7)

They just keep it to themselves when they are depressed... they want to be alone. (M, group 4)

Girls – they go out and get intimate with guys. (M, group 8)

Have sex. (F, group 3)

### **Asking for help**

When directly asked about whether young people would ask for help, the majority of participants were emphatic that young people would not talk to anyone.

No, not really. They are just in a crevasse. (M, group 4)

They would keep it to themselves. (M, group 2)

Most people probably wouldn't say unless someone actually asked them, they just commit suicide. (M, group 4)



Sometimes they might be angry at the person who could help them. Because teenagers think “I am not like that, I don’t need no-one.” They think the adults are against them, not with them. (M, group 8)

No, they think they are alright and they don’t need people to help them. (F, group 5)

No they don’t ask for help, they don’t show it, some of them don’t even know that they are depressed. (F, group 5)

In contrast, a minority of participants identified that they could talk or had talked to someone that they knew. The most common person for them to speak to was a tutor on their schooling programme, a few had spoken with a family member, a friend or a guidance counsellor when they were in school.

In four groups the issue of being referred to mental health services was discussed. Participants thought it was ‘*stink*’ to expect young people to go to a doctor and then perhaps be referred to a mental health service if they were depressed. Most students said they would not want to be referred to mental health services. The word ‘mental’ and not knowing the service providers personally were significant barriers to these young people. Several students thought that young people might harm themselves if they were referred.

It would be quite shocking (to be referred to a mental health service). (M, Group 8)

They would be very angry I suppose. (M, group 8)

I’d say see you later. (M, Group 6)

They would probably run away. (M, group 8)

They might be pretty bad and thinking well my life is crap anyway, so they would be going to a mental health institute that means they might be feeling crap and want to do something bad to themselves, like kill themselves. (M, group 7)

I would diss every appointment ... like try and not go...not be into it. (F, group 3)

I would rather stay in the (neighbour)hood. (M, group 6)

However this was not the only response, a small minority of students were more positive about mental health services including two who said that they had used these services.

### Interest in computerised programmes to help with depression

Participants were interested in a computer programme to help with depression, most thought it was *'mean'*<sup>3</sup>, *'all good'*, *'cool'* or *'a good idea'* and that they would like to try it or see what it was like. The main rationales for this interest were that they liked using the computer or playing computer games or because this would be easier than talking to someone. Some participants thought it might be particularly good for those who don't like talking.

Most, but not all, participants thought using a computer programme for depression would not prevent young people talking to a counsellor or a therapist.

I don't think it will stop them, (talking to someone else) I think it will just help them. (F, group 3)

This could build up more confidence (for talking to a counsellor or therapist). (F, group 3)

Participants thought that potential difficulties or downsides were a computer programme *'might not reach some people, everyone doesn't have the same problems so maybe you should see a counsellor'* or that *'talking is better'*. On the whole, participants agreed that a computer programme would be good to have as an option and it would be good to be able to try it out.

Both internal and external barriers to using a computer programme for depression were identified. The dominant concern was embarrassment or shame if other young people might realise that they were depressed.

Another common barrier identified was the lack of computers in some alternative schools and /or a lack of physical space in which to have computers.

Less commonly participants identified concerns with potential aspects of therapeutic games: for example *'it might be boring'*, especially if you were *'just sitting there and typing random things'*. Two students identified internal barriers other than embarrassment, these were *'stubbornness – 'Uh I don't need to do it'* or that if you were depressed you might not want to play a game.

Participants' main suggestions for overcoming barriers to using the programme were that the researcher should find ways to reduce embarrassment or reduce the need to ask for help. Specific suggestions were to deliver the programme to the whole class; or not to make it too obvious that it was about mental health (by including plenty of action, good music and a 'gamey' look).

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<sup>3</sup> Positive.

## Questionnaire responses

The pen and paper questionnaire administered at the end of 7 out of the 8 focus groups was completed by all 31 participants in these groups. Overall the participants were positive about the content of the prototype of the cCBT resource that they had seen, and were very positive about the look and style of it. Although students were invited to write any additional comments that they had not said in the group, few written comments were made except for general positive remarks.

Approximately 60% (19 out of the 31) of respondents reported that they had felt down or low for more than a few days in a row.

Most participants said that they would want to use a programme such as this if they were feeling down (Table 10).

**Table 10: Numbers of participants who would want to use a programme such as SPARX if they were feeling down**

<b>Group (n)</b>	<b>Number (%) who would want to use a programme such as SPARX if they were feeling down</b>
Total (31)	26 (84)
Maori (18)	18 (100)
Non-Maori (13)	8 (63)
Male (21)	18 (86)
Female (10)	8 (80)
Participants who had felt down for more than a few days in a row (19)	16 (84)
Participants who had not felt down for more than a few days in a row (12)	10 (83)

## Discussion

In this study adolescents alienated from mainstream education were familiar with the concept of depression and reported serious, often harmful behaviour as key responses to feeling depressed. These young people reported that seeking help for depression in their peer group was very limited, including from informal sources such as friends or family. Participants were dismissive of models of care requiring young people to ask for help from a General Practitioner or mental health service and some thought that referral to mental health services might make young people uncooperative or even suicidal. There was a high level of interest in computerised therapy, particularly if this could be provided without peers knowing that they were depressed.

While risky behaviour, self-harm and substance use have been described as responses to depression in a number of studies (Birmaher, et al., 1996) the emphasis and rate of harmful or potentially harmful responses towards self and others here is concerning. It may be that depression is particularly toxic for adolescents who are alienated from mainstream education and who typically face multiple challenges.

Gulliver and others (2010) described low rates of recognition of symptoms as a significant barrier to help seeking among young people and the New Zealand Ministry of Health (2010) reported low health literacy among Maori. However the current findings suggest that lack of knowledge about depression is not necessarily the major barrier to accessing help here. Rather, not seeking help despite being distressed appears to be particularly important for these students.

The reluctance to seek help from professionals described in this study is consistent with, although perhaps more severe than, previous studies of young people (see Barker, 2006 or Gulliver et al., 2010 for reviews). In multiple studies it has been shown that young people often do not seek help even when they have significant difficulties; and that when they do seek help, they prefer to do this from people that they know well (Booth, et al., 2004; Breland-Noble, Burriss, & Poole, 2010; Ciarrochi, Wilson, Deane, & Rickwood, 2003; Gulliver, et al., 2010; Murray, 2005; Rickwood, et al., 2007; Wisdom, Clarke, & Green, 2006). The universality of these findings suggests that actively asking help outside ones known social context is a challenging and perhaps unrealistic task for many adolescents.

Limited help seeking among young people alienated from mainstream education should be considered along with the suggestion that being referred to a mental health service might lead some to react dangerously. Together these findings highlight the importance of shaping service provision to match the developmental needs and preferences of this vulnerable group of young people. Models of mental health care predicated on seeking help from a health professional, whom the young person may not know well, and the possibility of being referred to a mental health service, do not fit at all well with the preferences expressed here.

The students in this study were very positive about computerised therapy. This contrasts with Stallard, Richardson and Velleman (2010) who found that only 25% of young people using CAMS services were keen to use a computer programme and with Ryan, Shochet & Stallman (2010) who found that about half of university students thought they would use an online programme to support student wellbeing. It may be that computerised therapy is particularly appealing to our sample or to young people who are not seeking help elsewhere. We did show the participants a level of SPARX. It is possible that seeing the programme might have engendered more positive responses than simply hearing about the idea.

Participants in this study thought that computerised therapy might make it easier to talk to people, and promote rather than reduce seek other help seeking. This is important finding to test further as the

concern that computerised therapies might decrease access to face to face assistance is a significant issue among health providers (Stallard, Richardson, et al., 2010).

The high level of interest in computerised therapy shown by these young people suggests that computerised therapy may provide a way of addressing depression in this group, especially if access can be offered through a provider that the young person knows well and can be achieved without embarrassment. This could be achieved by offering the intervention to all students within high risk groups, by utilising gatekeepers such as tutors if this can be managed without stigma, or perhaps making appealing programmes available directly to young people over the internet.

### **Limitations**

This a focus group study with a specific, mainly male, mainly Maori and Pacific population of young people in alternative schooling in New Zealand. This is useful for 'hearing the voices' of participants and for generating new understandings. However the methods are not designed to test hypotheses nor to generalise to other populations.

There are further limitations including that participants were not selected on the basis of depressive symptoms. Although the majority said that they had experienced feeling down, we did not test whether they had diagnosable depression. Work by Wilson and others (Wilson, 2010; Wilson, et al., 2007) suggests that young people who are less depressed may be more positive about seeking help than young people who are more distressed. Additionally, participants' statements in front of others may be different from what they might say alone and different again from what they would do in practice. Further focus groups in this study were relatively short, were conducted by a New Zealand European researcher and a general inductive analysis was used; it is possible that longer, more in-depth discussions, culturally embedded researchers and other analyses may have increased depth of findings.

Thus findings should be regarded as preliminary and subject to further investigation. However, there is very little research with this community of young people. The significance of their perspectives should not be overlooked.

### **Conclusions**

Findings from this small study suggest that young people alienated from mainstream education address the problem of depression in very concerning ways that include self harm and violence. They are unlikely to seek help from general practitioners and even less so from mental services and to get them to do so would require considerable, perhaps unrealistic, changes to the young people's existing attitudes and perceptions.

We need strategies that help young people to receive evidence based treatment while respecting their developmental needs and preferences. Appealing computerised therapies, offered in non-stigmatising ways, appear to be one promising option.

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## **Chapter 7: STUDY 3: A PRAGMATIC RANDOMISED CONTROLLED TRIAL**

### **Preamble**

This chapter reports Study 3 (see Figure 2), the trial of the cCBT programme among adolescents in alternative schooling programmes for those alienated from mainstream education. The rationale for the trial and the choice of a pragmatic approach are discussed in Chapter 4. The methods for this trial were finalised after the provider interviews (Study 1) and most of the youth focus groups (Study 2) had taken place. These studies had highlighted several issues relevant for the design of the trial. These issues are discussed below. The remainder of the chapter consists of the published article reporting this trial. The revised article was submitted in September 2011; hence the literature reviewed in the article is current to that time. Relevant literature published subsequent to submitting this and before the finalisation of this thesis is included in Chapter 9.

### **Issues identified in Studies 1 & 2 relevant for the design of the trial.**

Interviews and focus groups with providers and young people identified several issues relevant for the design of the trial. Firstly, in focus groups young people were enthusiastic about cCBT and expressed little interest in other forms of mental health intervention. This suggested that randomisation to non cCBT conditions might not be desirable to young people participating in a trial. This could lead to reduced recruitment or high rates of drop out among students randomised to a non cCBT condition, which would reduce the validity of the findings (Kaltenthaler, Sutcliffe, et al., 2008). Thus, in order to respond to young people's preferences and maintain an experimental design, I developed an immediate compared to delayed intervention design. The primary outcome measures were compared between the two groups at 5 weeks (prior to the delayed group beginning the intervention and after the immediate treatment group had had opportunities to complete it). Interestingly, in the UK Stallard et al. (2011) initially began a trial of cCBT in which adolescents were randomised to cCBT or waitlist control; however, in order to increase recruitment this was changed to a very similar design to mine, utilising an immediate or approximately 4 week delayed intervention.

Secondly, I had initially conceptualised a trial including only students who had depression or difficulties with low mood. However, provider feedback suggested that many providers did not wish to identify students with mental health difficulties. Youth feedback also identified that indicated interventions (i.e. interventions for individuals with symptoms) were problematic, in that students might hide or not

recognise that they were depressed, might not ask for help and would not wish to be seen as having a problem by their peers. Both young people and providers were interested in cCBT for whole class groups. Given the goal of investigating effectiveness under real world conditions, I developed recruitment plans with each participating site, to reflect how they would be likely to use cCBT outside of a research study. Thus providers could offer cCBT to the whole group (an 'opt out' strategy) or to identified individuals (opt in). This flexibility is appropriate for a pragmatic trial (Thorpe, et al., 2009). Given the high rates of depressive symptoms among students in AE, the concerning ways of dealing with depression described in Study 2, and the skills focus of SPARX, the option of an opt out recruitment strategy was reasonable and this was approved by the Ethics Committee.

Thirdly, informal provider feedback suggested that the total amount of time for participation in the trial should be limited to just one school term, due to high rates of moving house and changing course among students. This also kept the time requirements of the study simple for providers. Thus the trial was designed so that students could complete 1-2 levels of the seven levels of SPARX per week over a five week period, with a five week follow up interview for students in the initial treatment group.

Only one issue specific to programme content was raised in provider interviews. Providers suggested that there should be greetings in many different languages at the opening of the SPARX programme. They considered that greetings only in English and Maori would be off-putting for some of their clients. This feedback was incorporated and the programme adjusted accordingly.

Thus findings from Studies 1 and 2 allowed the development of the trial to better meet the needs of providers and young people.

# **'A Pragmatic Randomised Controlled Trial of computerised CBT (SPARX) for symptoms of depression among adolescents excluded from mainstream education.' (2011) *Behavioural and Cognitive Psychotherapy***

**Theresa Fleming, Robyn Dixon, Christopher Frampton, Sally Merry**

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## **Abstract**

**Background:** Adolescents excluded from mainstream education have high mental health needs. The use of computerised Cognitive Behavioural Therapy (cCBT) has not been investigated with this group. **Aims:** To test the effectiveness of the 'SPARX' cCBT programme for symptoms of depression among adolescents in programmes for students excluded or alienated from mainstream education. **Method:** Adolescents (32; 34% Maori, 38% Pacific Island, 56% male) aged 13-16 with Child Depression Rating Scale Revised (CDRS-R) scores indicating possible through to almost certain depressive disorder, were randomised to SPARX to be completed over the following 5 weeks (n=20) or to wait list control (n=12). Assessments were at baseline, 5 weeks and 10 weeks. Those in the wait condition were invited to complete SPARX after the 5 week assessment. **Results:** Most participants (n=26, 81%) completed at least 4 levels of SPARX and 22 (69%) completed all 7 levels. Among the 30 (94%) participants who began treatment as randomised and provided 5 week data, significant differences were found between cCBT and wait groups on the CDRS-R (baseline to 5 week mean change -14.7 versus -1.1,  $p < 0.001$ ), remission (78% vs. 36%,  $p = 0.047$ ) and on the Reynolds Adolescent Depression Scale (-4.6 vs. +3.2  $p = 0.05$ ) but not on other self rating psychological functioning scales. In intent-to-treat analyses CDRS-R changes and remission remained significant. Gains were maintained at 10 week follow up. **Conclusions:** SPARX appears to be a promising treatment for students with symptoms of depression who are in alternative schooling programmes for those excluded from mainstream education.

**Keywords:** Adolescents, depression, CCBT, computer

## Introduction

School retention and educational achievement are predictive of good health status (Freudenberg & Ruglis, 2007). Young people who leave school under the minimum school leaving age have high rates of a broad range of health and social problems such as depression, substance abuse, criminal offending and reduced earning potential (Ou, 2008). Partly to address these issues, Alternative Education and other alternative schooling programmes (such as youth wrap-around and transition programmes) for young people who are excluded or alienated from mainstream education have been established. Students in these programmes have high mental health needs. For example, those in Alternative Education (AE) in New Zealand have approximately twice the rates of depression and more than three times the rates of suicide attempts as their peers in mainstream high schools (Clark, et al., 2010; Denny, Clark, & Watson, 2004).

Evidence based treatments for adolescent depression are available, with Cognitive Behavioural Therapy (CBT) being the treatment of choice for young people with mild to moderate depression (National Institute for Health and Clinical Excellence, 2005). Computerised CBT (cCBT) has been shown to be effective and acceptable for adults with depressive disorders (Andrews, et al., 2010) and holds promise in terms of potentially increasing the availability of CBT for teenagers. There have been positive or promising results for cCBT for depression among young people utilising General Practice care (Van Voorhees, et al., 2005; Van Voorhees, Fogel, Reinecke, et al., 2009), utilising mental health services (Abeles et al., 2009; Stallard, et al., 2011) and for students attending high schools (O'Kearney, et al., 2006; O'Kearney, et al., 2009). However there is a lack of evidence regarding the use of cCBT for adolescents alienated or excluded from mainstream high schools. While cCBT may be just as effective for this group as for other teens, they are different from many research samples in terms of socio-economic status (mainly being from higher deprivation communities), gender (mainly male), age (mainly 13-16 years) and ethnicity (typically including high numbers of indigenous and ethnic minority young people). In addition, young people in alternative schooling have high rates of exposure to family stressors, low rates of literacy, low rates of help seeking for mental health needs and a lack of engagement with mainstream health services (Clark, et al., 2010; Smith, et al., 2007) which might mean different approaches are required.

We developed a cCBT programme called SPARX. SPARX has been tested in comparison to treatment as usual for young people in mainstream high schools, youth health services and traditional primary health care (Merry et al., submitted). In this smaller companion study we aimed to test the effectiveness of SPARX for students in alternative schooling programmes for adolescents excluded, or at risk of being excluded, from mainstream education at and under the New Zealand minimum school leaving age of 16 years. Specifically we aimed to investigate whether SPARX reduced symptoms of depression, anxiety

and hopelessness and improved quality of life and locus of control scores, compared to those wait listed for SPARX. The study used pragmatic design features to provide an indication of the potential effectiveness of SPARX in alternative schooling environments.

## **Methods**

### **Trial design**

The study employed an immediate vs. delayed intervention randomised controlled trial. The intervention was the 7 module SPARX cCBT programme, to be completed at a rate of 1-2 modules per week, from week 0 to week 5 for the immediate treatment group and weeks 5-10 for the delayed treatment group. Assessments were carried out by TF at baseline and at 5 and 10 weeks.

### **Participants**

Participants were recruited from:

- Three Alternative Education (AE) schools. In New Zealand these are educational programmes for teenagers aged 13 ½- 15 ½ who have a history of school exclusions, behaviour problems or long term truancy and are considered to be at risk of major behavioural difficulties in a usual high school environment (O'Brien, et al., 2001).
- An educational programme for students aged 12 to 16 years who have been temporarily excluded and are considered at risk of permanent exclusion from school.
- A transition programme for young people who have been in AE and are now aged 15 ½ -16 ½ and are not ready for work, school or tertiary training.

Recruitment plans were developed in conjunction with staff at each site to reflect how such an intervention would be likely to be implemented in that site. In 4 out of the 5 study sites all students were invited to participate, irrespective of the presence of depressive symptoms (opt out). In one site all students were informed about the study and were able to ask to participate or have a tutor suggest they participate (opt in).

Students were excluded if: they had severe depression, high suicide risk or other mental health issues which may have meant that they were not safe on the computer programme; they had a disability, or insufficient proficiency in English that may have resulted in them not being able to use the programme or not being able to comprehend the functioning scales; or they were not intending to remain enrolled in the participating schooling programme for at least 10 weeks. Students with no or minimal symptoms of possible depression (raw CDRS score under 30, indicating a depressive disorder is unlikely) were allowed to participate and were randomised, however for the purposes of this analysis of effectiveness their data were excluded.

Recruitment took place from July 2009 to June 2010. Written consent was obtained from participants, where they were aged under 16 consent was also obtained from a parent or guardian. Ethics approval was given by the Northern Y Regional Ethics Committee, reference number NTY/09/04/036.

### **Intervention**

The SPARX programme consisted of 7 modules or 'levels', each of approximately 30 minutes duration. The content was developed by clinical and academic experts at the University of Auckland in partnership with a computer games company, and with advice from young people and from Maori, Pacific and Asian cultural advisors. Content was based on CBT and included psycho-education, relaxation skills, problem solving, activity scheduling, challenging and replacing negative thinking and social skills. The programme includes direct instructional content as well as narrative and experiential learning components. Voice over, written text and music were used. Each module involved meeting with the 'guide' who spoke in first person about dealing with depression, presented mood and safety checks, offered further help beyond the SPARX programme and outlined the purpose of the following level. Next the user entered the 'game world,' where they inhabited a personalised character and helped to restore the balance in the game world by using skills from a 'shield against depression'. An overarching narrative, metaphor and visual and verbal memory aids and a range of game elements (from helping characters to solve problems to shooting negative thoughts) were used. At the end of each level the user returned to the guide who again communicated with them in first person, reflected on the learning and how that might be applied in real life and set homework challenges. Images from the programme can be viewed at [www.sparx.org.nz](http://www.sparx.org.nz).

Students completed SPARX during class time under minimal supervision from their educational service provider. One site had a suite of computers and students completed SPARX in two groups. The remainder had 1 or 2 computers so students completed SPARX individually. Each site was visited or telephoned weekly by TF (a PhD candidate with experience working as a clinician in adolescent health and mental health services) to address any safety concerns or problems that may have arisen or to support students in the use of the programme. In two sites the tutors had indicated that they were too busy to organise the intervention and so students were prompted to do a module of SPARX if they hadn't already done so during weekly visits.

### **Measures and Outcomes**

Demographic data were collected at baseline. Where students reported more than one ethnicity they were categorised using the NZ Census ethnicity prioritisation method (Ministry of Health, 2004).

The primary outcome measure was the Children's Depression Rating Scale, Revised (CDRS-R), (Poznanski & Mokros, 1996). This is an observer-rated scale with good sensitivity to change (S. Brooks & Kutcher, 2001), and well established reliability and concurrent validity (Myers & Winters, 2002).

The following self-report scales were used as secondary measures: Reynolds Adolescent Depression Scale (RADS-2) (Reynolds, 2002); Paediatric Quality of Life Enjoyment and Satisfaction Questionnaire (PQ-LES-Q) (J. Endicott, Nee, Yang, & Wohlberg, 2006); Spence Anxiety Scale (S. H. Spence, Barrett, & Turner, 2003); Kazdin Hopelessness Scale (HPLS) (Alan E. Kazdin, French, Unis, Esveldt-Dawson, & Sherick, 1983) and the Children's Nowicki-Strickland Internal-External Control Scale short (20 item) form (CNSIE) (Nowicki & Duke, 1983). Students completed these themselves or, if they preferred, had them read aloud by the researcher.

Remission was defined as a reduction in raw score on the CDRS-R to below 30. Clinically significant change was defined as remission or a reduction of at least 30% in symptoms on the CDRS-R. An adverse event was defined as an episode of self harm or an increase in depressive symptoms of 5 or more points in CDRS-R raw score or an adverse change in category on the CDRS (for example, from 'possible' to 'likely' depression).

### **Randomisation and blinding**

Randomisation was carried out in a 1:1 ratio using a computer generated randomisation sequence. Allocation was stratified by study site and arranged in permuted blocks. Allocation concealment was ensured by allocating each participant a unique study number in sequence as they met the researcher (TF). This occurred prior to eligibility being assessed as consultation had identified that young people wanted to test the programme regardless of whether they had difficulties, and did not want their level of distress to be identifiable to their peers. Thus the same process was used for all students; however analysis was of those who had symptoms of possible depression at baseline. A sealed envelope for each study number containing treatment allocation had been prepared in advance by an independent research assistant. Following baseline assessment the young person opened this envelope with the researcher and access to immediate or delayed treatment was arranged.

It was not possible to blind participants to their treatment allocation. The researcher was also unblinded after the baseline assessment. However, 19% of CDRS-R interviews were audio recorded and were scored by a research assistant blinded to allocation; these scores were compared to the assessor's scores by an independent statistician. No systematic inter-rater differences were found (means 25.7 and 26.4 with a co-efficient of between-rater variation (C.V) of 7.9%).

### **Statistical Analysis**

This exploratory study was powered (80% power) to detect a large effect size ( $d \geq 1.0$ ) with a sample size of 15/ group allowing up to 50% loss of participants at follow up.

Although all participants ultimately received SPARX, comparisons of changes from baseline to week 5 between the randomised groups were planned as the main analyses of effectiveness. The comparison of 5 week and 10 data for those who received SPARX first provided an estimate of the maintenance of



changes. A further analysis tested whether changes associated with SPARX were the same for those who received it first compared with those who waited.

As a small study, the main analyses utilised all participants with pre and post SPARX assessments who had not broken treatment allocation. An intention-to-treat analysis was also undertaken although the sample size was not adequate for this to be conducted as a main analysis. Statistical analyses were carried out using SPSS software. For primary and secondary outcome measures the changes from baseline to five weeks were compared between SPARX and wait groups using ANCOVA with the baseline level as the covariate. Differences between groups at 5 weeks in remission and in clinically significant reductions in symptoms were tested using Fishers Exact Test. A series of paired T-tests compared post treatment to follow up changes for those randomised to immediate SPARX. An Analysis of Variance compared the magnitude of change (pre-post treatment) between groups. A two-sided p-value of smaller than or equal to 0.05 was taken to indicate statistical significance.

Out of a total of 12 104 assessment items 88 were missing. Where up to 5 of the 14-30 items on any questionnaire were missing then the total scores were calculated from the available data and weighted to compensate for the missing items. In the two situations where more than 5 items were missing from a single scale, that scale was considered missing at that time point. As there is considerable correlation amongst the outcome measures no correction for multiple comparisons was made.

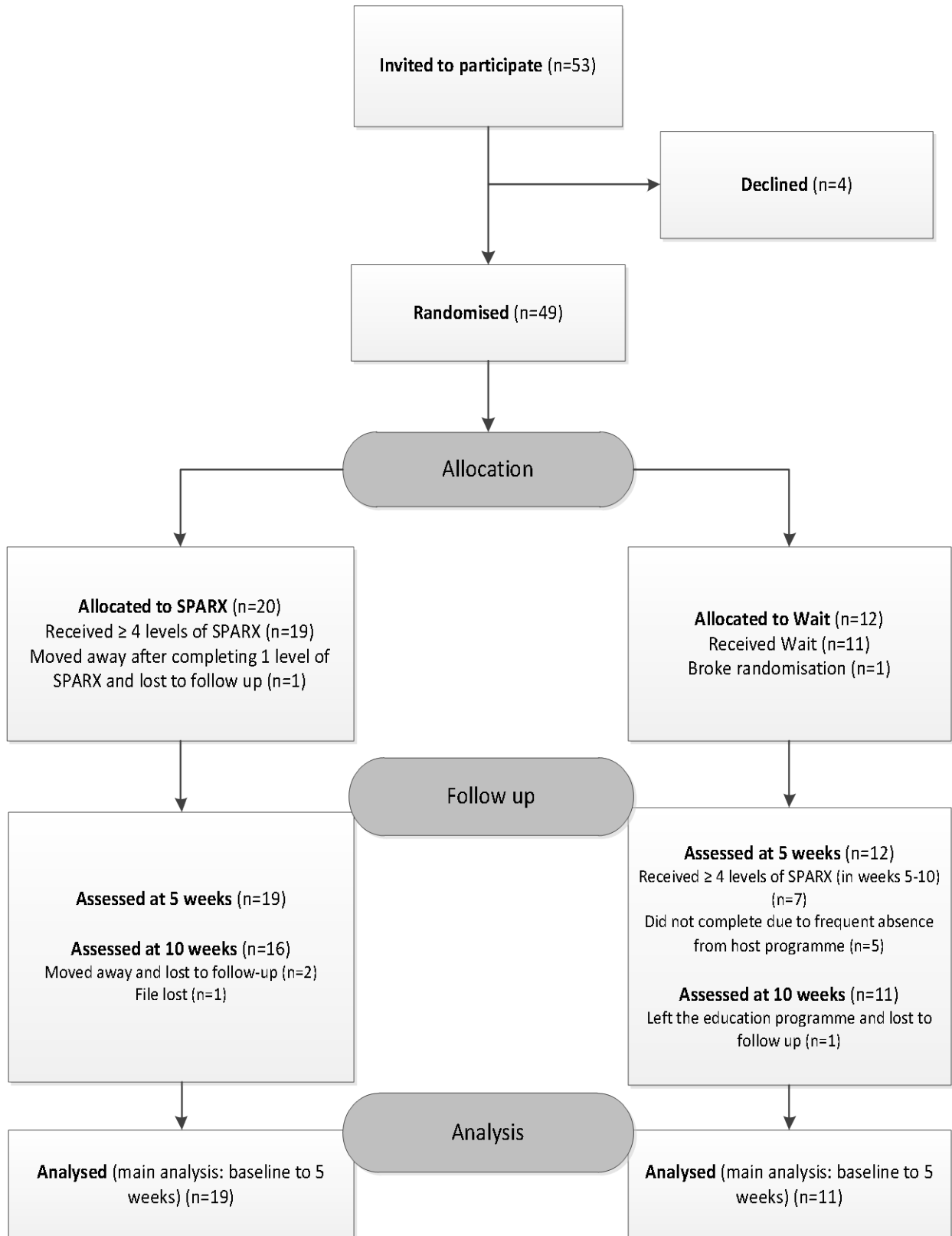
The trial was registered with the Australian New Zealand Clinical Trials Registry, registration number ACTRN1261000074099. The statistical analysis was planned and documented prior to data analysis.

## **Results**

### **Participant flow, completion rates**

The participant flow is shown in Figure 3. There were between 1 and 11 students recruited from each of the 5 sites using block randomisation for each site. In the 4 'opt out' sites 51 young people were approached, 3 declined. Of those excluded 12 had no or minimal symptoms of depression, all 12 wished to participate however as planned their data were excluded from this analysis. In the one 'opt in' site no students asked to be in the study, tutors invited two to participate, one of whom agreed. These processes resulted in uneven group sizes (20:12).

**Figure 3: Flow chart of participants in the trial**



Baseline data were available for all 32 participants, five week assessment data for 31 (97%) and ten week assessment data for 27 (84%) of participants.

Twenty-six (81%) of participants completed 4 or more sessions of SPARX, with 22 (69%) completing all 7 levels. Completion rates were higher in Group 1 - SPARX first (19/20 completed four or more levels and 15/20 completing all levels) than in Group 2 - Wait first (7/12 completed four or more levels and 7/12 completed all levels). Most participants who did not complete reported running out of time and said that they did wish to finish. In Group 2, one participant broke randomisation and did several levels of SPARX while allocated to wait; this young person completed the 5 week assessment but then left the schooling programme and was lost to follow up.

The primary analyses were carried out with all 30 (93.7%) participants who had baseline and 5 week data and had not broken treatment allocation.

### **Baseline data**

The mean age of participants was 14.9 years (range 13-16, SD=.79), 18 (56%) were male, 11 (34%) were Maori, 12 (38%) were Pacific island, 8 (25%) were New Zealand European and 1 was of other ethnicity. All participants had a CDRS-R score of over the 70<sup>th</sup> percentile of depressive symptoms as detailed in the CDRS-R manual (Poznanski & Mokros, 1996). Although treatment groups were different sizes they were comparable in terms of severity of baseline symptoms (Table 11).

### **Outcomes**

There were significantly greater reductions in CDRS and RADS scores from baseline to week 5 for the SPARX group compared with those who waited; however, there were no significant differences in the changes in the remaining self report measures (Table 11). Effect sizes were 1.61 for CDRS-R and 0.77 for RADS-2. Those in the SPARX group were significantly more likely to be in remission or to have had a clinically significant reduction in symptoms than those in the wait group (Table 11).

### **Effect of treatment for wait group**

The group allocated to wait first also improved when they were able to do SPARX. The magnitude of improvement was not statistically different from the group that did SPARX initially. Pre-post SPARX (week 5 to week 10) mean changes (with 95% confidence intervals) for those allocated to wait first were: CDRS-R: -13.2 (-10.1 to -16.2); RADS-2: -7.3 (-0.5 to -14.1); PQ-LES-Q: 3.7 (-0.1 to 7.6); HPLS: -1.1 (-2.9 to .6); Spence: 0.7 (-7.4 to 8.8); CNSIE: -2.1 (-0.2 to -4.1).

**Table 11: Primary and secondary outcomes at baseline and mean changes at 5 weeks<sup>1</sup>**

	Group 1: SPARX N= 19		Group 2: Wait N = 11		F (p) value
	Mean at baseline (95% CI)	Pre-Post mean change (95% CI)	Mean at baseline (95% CI)	Pre-Post mean change (95% CI)	
<b>Primary outcome</b>					
CDRS-R	39.6 (35.3 to 43.9)	-14.7 (-10.7 to -18.6)	39.5 (33.9 to 45.2)	-1.1 (-6.3 to 4.1)	18.11 (.000)
<b>Secondary outcomes</b>					
RADS-2	70.3 (64.0 to 76.6)	-4.6 (-9.3 to .2)	70.5 (62.2 to 78.8)	+3.2 (-3.0 to 9.4)	4.13 (.052)
PQ-LES-Q	36.6 (32.7 to 40.4)	1.3 (-2.3 to 4.9)	33.7 (28.7 to 38.8)	+1.74 (-2.96 to 6.5)	.023 (.881)
HPLS	4.3 (2.7 to 5.9)	-.6 (-.8 to -1.9)	5.6 (3.4 to 7.7)	0.5 (-1.3 to 2.3)	.901 (.351)
Spence	29.1 (22.8 to 35.3)	-.968 (-6.6 to 4.5)	26.4 (18.3 to 34.4)	-5.825 (-13.0 to 1.3)	1.20 (.283)
CNSIE	10.5 (8.8 to 12.2)	-2.1 (-3.6 to 0.7)	9.8 (7.5 to 12.0)	-0.2 (-2.2 to 1.7)	2.61 (.118)
				Fishers Exact Test	
Remission <sup>2</sup>	–	15 (78.9%)	–	4 (36.4%)	0.047
Clinically significant change <sup>3</sup>	–	17 (89.5%)	–	4 (36.4%)	0.004

<sup>1</sup> Data are for all participants who completed at least one level of SPARX in the group that they were randomised and completed 5 week assessment. <sup>2</sup> Remission is defined as decrease in CDRS-R raw score to under 30.

<sup>3</sup> Clinically significant change is defined as decrease in CDRS-R raw score to under 30 or a decrease of 30% or more in the CDRS-R raw score.

**Table 12: Maintenance of effects: mean scores on primary and secondary outcomes immediately post intervention (5 weeks from baseline) and at follow up (10 weeks from baseline) for participants who received SPARX immediately**

	Group 1 SPARX		T test p
	Post intervention	Follow Up	
CDRS-R	25.6	25.0	.707
RADS-2	67.6	69.0	.607
Spence	30.5	24.9	.080
HPLS	3.90	3.53	.672
PQ-LES-Q	36.8	37.0	.861
CNSIE	8.2	6.9	.107

### **Maintenance of effect**

Maintenance of effect was tested for participants who were randomised to SPARX immediately. There were no significant changes in outcomes from post treatment (5 weeks) to follow up (10 weeks) (Table 12).

### **Adverse Events**

There were a total of 6 adverse events. Four young people had an increase in depressive symptoms. Each of these young people was in the waitlist, pre-SPARX condition. There were 2 incidents of self harm reported; each was reviewed as per the study protocol and was found to be unrelated to the intervention. Both events were in the group allocated to SPARX first, with one event occurring during treatment and the other post SPARX, during the follow up period.

### **Intention to Treat Analyses**

Primary and secondary outcome analyses were re-run using Intention to Treat (ITT) analyses. Baseline data for the missing case in the SPARX group were brought forward. Week 5 data for the participant who broke allocation and received the intervention while allocated to wait were included in the wait group data. This resulted in CDRS-R pre-post mean changes of -13.9 (95% CI 10.0-17.9) for the SPARX group and -1.9 (95% CI -7.0+3.3) for the wait list;  $F 14.5, p = 0.001$ . The RADS pre-post mean change for SPARX was -4.5 (95% CI -9.0+0.1) and for wait list was +2.3 (95% CI -3.6+8.1);  $F$  value 3.4  $p = .075$ . Remission rates using ITT analyses were 15/20 (75%) of the SPARX group compared to 5/12 (41.7%) of those in the wait group (Fishers Exact Test  $p=0.130$ ). Clinically significant change was 17/20 (85%) for the SPARX group and 5/12 (42%) in the wait group (Fishers Exact Test  $p=0.018$ ).

## **Discussion**

The results of this small study suggest that the SPARX cCBT programme is engaging and may be effective in reducing depressive symptoms in adolescents excluded from mainstream education. There were high rates of completion of the cCBT programme. The cCBT group demonstrated improvements in depression scores over the wait list control as measured by the CDRS-R, RADS-2 and remission rates. The effects were maintained at 10 week follow-up. However there were no significant effects on measures of hopelessness, locus of control, anxiety, or quality of life.

In terms of the feasibility of cCBT, as well as in terms of impact on depressive symptoms, the results are promising. The alternative schooling sites had few computers and limited supervision was available. Additionally our finding that it was practical to offer the intervention to whole classes is important, given that majority of students had symptoms of possible depression and that embarrassment about being seen to be depressed and low rates of help seeking had been reported as major barriers to

treatment (Fleming, Dixon and Merry, submitted). Young people excluded from mainstream schooling often have multiple challenges and many had previously tried other interventions; so it was pleasing that this relatively short programme was associated with a reduction in depressive symptoms.

A recent systematic review (Richardson, et al., 2010) identified one study of an online chat group for adolescents (Gerrits, van der Zanden, Visscher, & Conijn, 2007) and 5 other studies of cCBT for depression among adolescents. These included universal trials (of all students in a year group) of “MoodGYM” in a boys and in a girls high school (O’Kearney, et al., 2006; O’Kearney, et al., 2009); and studies among young people utilising General Practice (Van Voorhees, et al., 2005; Van Voorhees, Fogel, Reinecke, et al., 2009) or mental health services (Abeles, et al., 2009). Since that review an additional trial of cCBT (“Think, Feel, Do”) with young people utilising CAMS services (Stallard, et al., 2011) has been published. No previous research regarding the use of cCBT with adolescents who were neither in mainstream schooling nor getting help from health services was found. Of the existing studies, only those testing “MoodGYM” (O’Kearney, et al., 2006; O’Kearney, et al., 2009) and “Think, Feel, Do” (Stallard, et al., 2011) were randomised controlled trials comparing cCBT to non cCBT conditions.

The research protocol for the current study was finalised after consultation with alternative school students and providers. This led to a shorter follow up period than we would have preferred to fit in with the preferences of the schooling programmes and to minimise loss to follow up. However participants were recruited more quickly than expected. This contrasts with many computerised therapy trials (Waller & Gilbody, 2009). It is notable that in study sites where all students were invited to participate, levels of recruitment and completion were high. In contrast, the one study site which relied on students help seeking or being suggested by a staff member resulted in only one participant.

The unequal sample sizes of the two groups were unfortunate but does not represent any bias in the group allocation or in the drop-outs. The baseline symptoms in the two treatment groups were comparable and fewer than expected students dropped out of treatment so the sample size remained adequate for the intended main analyses.

Once students had begun SPARX, most completed it. Again, this is in contrast to many studies of cCBT (Waller & Gilbody, 2009) but it is consistent with the “Think, Feel, Do” trial. Both “Think, Feel, Do” and SPARX are specifically designed for use with young people and include graphic interfaces rather than being text based. Further, in both of these trials participants were randomised to cCBT immediately or after a short delay. It may be that these cCBT interventions were particularly engaging or that this study design was appealing to young people. The prompting by tutors or the researcher and the fact that the intervention was offered during class time may have also been factors in our high completion rates.

Non completion was higher in the delayed treatment group. Most participants reported that this was because they ran out of time, usually because of frequently being absent from the course. It is possible that the delay might have had an impact on motivation. This could be tested in future research.

The finding that cCBT appeared to reduce depressive symptoms is consistent with positive findings regarding the impact of cCBT on depression among adults (Andrews, et al., 2010) and with positive or promising findings from previous studies in young people (Richardson, et al., 2010).

We did not detect an effect for anxiety, locus of control, hopelessness or quality of life. Abeles et al. (2009) and Van Voorhees et al. (2009) reported reductions in anxiety of cCBT programmes for adolescent depression. However others have not reported anxiety findings (O’Kearney, et al., 2006; O’Kearney, et al., 2009; Van Voorhees, et al., 2009) or have had non-significant findings (Stallard et al., 2011). Although SPARX includes relaxation techniques, baseline anxiety scores in this group were under the cut-off associated with children at high risk for anxiety (S. Spence, 1997), hence we might have encountered a floor effect (Everitt, 2002). The other negative findings may indicate that SPARX had no impact on quality of life, hopelessness or locus of control in this group. This should be tested further in future research.

Encouragingly, therapeutic gains were maintained at 10 week follow up. The longer term impacts of cCBT within this group should be investigated further.

This study has a number of limitations. These include its small size and short follow up period. As a small study with limited funds and working in often poorly resourced sites, the introduction to the programme, recruitment and assessments were completed by one researcher. Care was taken to ensure adequate allocation concealment, which was done centrally by computer, however the researcher was not blinded when conducting post intervention and follow up assessments. Although blind review of audio recorded interviews did not suggest any bias, and all other measures were self-report scales this remains an important limitation.

Outcome measures used in this study have not been validated for use with this specific group. This may be significant (A. L. Stewart & Nápoles-Springer, 2003). For example questionnaire items for the CNSIE scale, are aimed at a 5th grade level of literacy (Nowicki & Strickland, 1973) which may be a higher level of literacy than that of some AE students.

Thus the current findings should be viewed as preliminary. Nevertheless, given the small number of trials regarding cCBT for depression in young people, and the lack of research for young people excluded from mainstream education, the findings are useful.

## Conclusion

Findings from this small pragmatic study suggest that the SPARX cCBT programme is engaging and appears to be a promising intervention for depressive symptoms among young people in alternative schooling programmes for those excluded or alienated from mainstream education. These findings with this vulnerable group suggest that cCBT may hold promise for young people who are reluctant to engage in traditional health services and who have poor health outcomes.

## Acknowledgements and Conflict of interests

The New Zealand Ministry of Health provided funding for the development of SPARX. Theresa Fleming is supported by a Top Achievers Doctoral scholarship from the New Zealand Tertiary Education Commission. Theresa Fleming and Sally Merry contributed to the development of the SPARX programme and the intellectual property of SPARX is owned by Uniservices at the University of Auckland.

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## Afterword

This study was not designed to investigate rates of depression among alternative schooling students; however, the proportion of participants identified as having symptoms of possible depression was very high. This was not discussed in this article as it had little direct bearing on the aims of that study. However, this is reviewed briefly here as it is important to the overall research.

In sites where all students were invited to participate, 48 out of 51 (94%) did so; of these, over 70% (65% of males and 81% of females) had symptoms of possible depression using the Children's Depression Rating Scale-Revised (CDRS-R) (Poznanski & Mokros, 1996). Using the Reynolds Adolescent Depression Rating Scale-2 (RADS-2) (Reynolds, 2002), 27% of males and 19% of females had clinically significant symptoms of depression. These are high rates and the two measures provide quite different indications. For both the CDRS-R and RADS-2, the mean score for all participants was fairly close to the cut off for symptoms of possible depression (CDRS-R raw score of 30 or over) (Poznanski & Mokros, 1996) or for a clinically significant level of symptoms which impair daily functioning (RADS-2 score of 77 or over) (Reynolds, 2002); however, on the CDRS-R most scores were above the cut off, while on the RADS-2, most were below it (CDRS-R mean 35: RADS-2 mean 65). The correlation between the two measures was 0.66; this is similar to that reported in previous research (Shain, King, Naylor, & Alessi, 1991). The CDRS-R was utilised in the study as it is sensitive to change (S. Brooks & Kutcher, 2001; Mayes, Bernstein, Haley, Kennard, & Emslie, 2010), while the RADS-2 is simple to administer and community norms are available (Myers & Winters, 2002) (see Appendix D for more detail about these measures). The CDRS-R measures the severity and impact of symptoms, while RADS-2 emphasises frequency. Neither tool provides a clinical diagnosis. The sensitivity of the RADS-2 is fairly low (S. Brooks & Kutcher, 2001), with 38% (Reynolds, 1987) and 32% (Jean Endicott & Spitzer, 1978) of subjects diagnosed with depression not scoring over the cut off on RADS. Hence the proportion of students scoring over the cut off on RADS-2 is likely to underestimate the burden of depression (S. Brooks & Kutcher, 2001). In general, clinician rating scales (such as the CDRS) are considered more accurate and sensitive than measures which rely on self report (A. Brooks, Ryder, Carise, & Kirby, 2010; Roberts, Lewinsohn, & Seeley, 1991). The CDRS-R correlates highly with depressive disorders, but its specificity is not well established (Guo, Nilsson, Heiligenstein, Wilson, & Emslie, 2006; Myers & Winters, 2002). It does include items such as difficulty concentrating, irritation, low self esteem and morbid thoughts, which are not specific to depression. Hence it might inflate estimates of depression among those who have other difficulties (Guo, et al., 2006).

Thus these incidental findings suggest that rates of clinically significant symptoms of depression were high in this group, and using the broader criteria of 'symptoms which may have been caused by depression', rates were very high. The implications of this are considered in chapter 9.

Another issue that warrants discussion is participant literacy and what impacts this may have had. In consultation prior to this trial, AE students indicated that the questionnaires proposed for use in the trial were not too burdensome (neither too many, nor too long), and no young people suggested that they might be too hard to read. However, as noted in the publication, none of these measures have been specifically validated for use in this population group. For this reason, and because literacy challenges are common in this group (Bruce and Ferguson, 2011), at each assessment I invited each student to have questionnaires read out to them or to read them themselves. Several students opted to have them read out while the majority read them themselves. It is possible that having questions read aloud may have resulted in different responses from completing them alone. Further, if students' literacy reduced their ability to comprehend questionnaires, then the sensitivity of the outcome measures would be reduced. Ideally, future research would address this issue. Questionnaires could be validated for this group and alternative processes, such as computerised questionnaires with voiceover, could be considered.

## **Chapter 8. STUDY 4: ADOLESCENT, PARENT AND PROVIDER FEEDBACK**

### **Preamble**

This chapter reports Study 4, parts one and two (see Figure 2). These utilised interviews and questionnaires with adolescents who had taken part in the trial of cCBT in alternative schools (part one) and interviews with their parents or caregivers and alternative schooling providers (part two). Data gathered with adolescents were relatively in-depth and are reported in the form of an article. Parent and provider feedback was less extensive and is presented here in the form of a brief report (not submitted for publication at the present time). The aim of each investigation was to explore participants' experiences of cCBT and their views of how it might best be used and/or enhanced.

User and stakeholder views are important. User satisfaction is an important component of good health care (Campbell, et al. 2000). Satisfaction affects users' decisions regarding accessing care in the future (S. M. Campbell, et al., 2000) and might influence the uptake of the intervention by those with whom they communicate. Feedback from users offers opportunities to understand whether and how a programme is effective, how a programme is used and how it might be improved (Oakley, et al., 2006). Similarly, family members and service providers who work closely with the target group might have insights into the effectiveness of programmes and how they might be improved (Kendall et al., 2009). If service providers are to have a key role in providing access to programmes and in supporting young people to use them, then their satisfaction with the content of programmes and how they are provided is critical (Aarons, et al., 2009). Utilising multiple perspectives provides richer insights than relying on any one set of informants alone (Kendall, et al., 2009).

There has been very little investigation of the views of young people who have used cCBT and very little investigation of the views of their families or of providers who assisted them. I completed interviews and questionnaires with adolescents once they completed the cCBT programme and conducted brief interviews with parents/caregivers and with alternative schooling providers.

The interviews with young people included specific research questions which had been raised in studies one and two. For example, providers had been concerned that the use of cCBT might reduce the use of personal, human support. This was explicitly considered here in interviews with young people. The issue of whether young people who need help might be targeted, or whether in practice they would be unlikely to identify themselves or to be identified by alternative schooling providers, had also been raised in each of the previous studies and so was explored further here.

To avoid an overlong and complex presentation the two parts of Study 4 are presented separately as each explores differing questions. The quotes from participants in Study 4 are included in tables. This is a method often used in the presentation of interview data in psychiatry journals; for example, see the following investigations of cCBT: Beattie et al. (2009), Stallard et al. (2010), Iloabachie et al. (2011). The literature reviews and discussions for both parts of Study 4 were finalised in April 2012 and are up-to-date as of the time of completion of this thesis. Further details of data checking processes not detailed in this section are described in Appendix C.

# Part 1: 'Calms you down and smooths the way: educationally alienated adolescents' views on in the impact and utility of computerised CBT (SPARX).' *In Review*

Theresa Fleming, Sally Merry

Submitted 20 5 12, as at end of May 2102, this is receiving a full review for *Behavioural and Cognitive Psychotherapy*.

## Abstract

**Background:** Computerised CBT (cCBT) appears promising for depression among adolescents; however, little is known about how users experience cCBT or view its use. **Methods:** Semi-structured interviews were completed with 39 adolescents (30 with symptoms of possible depression at baseline; 24 males; 15 Māori; 12 Pacific Island; all 13-16 years) and self-report questionnaires with 38 adolescents (1 participant was missed) who took part in a pragmatic trial of cCBT ('SPARX') for symptoms of depression in alternative schools (Alternative Education and other schooling programmes for adolescents excluded or alienated from mainstream education). **Results:** Satisfaction was high; participants considered that cCBT was useful (87%). Those with and those without symptoms had similar views. Most experienced cCBT as helpful and fun. Perceived benefits of cCBT were primarily expressed in terms of increased calmness and reduced anger and fighting or improved relationships. Most considered that cCBT might smooth the way to therapy for those who needed more, making users more, rather than less likely to ask for help. Participants considered that cCBT is quite a different experience from counseling and most thought it would be helpful for all students in alternative schools, whether or not they had symptoms of depression. **Conclusions:** Educationally alienated adolescents considered cCBT beneficial and thought it should be used universally in alternative schools. Service users' insights have important service delivery implications.

**Key words:** adolescents, depression, alternative education, computer, CBT, consumer views

## Introduction

Depressive disorders and sub-threshold symptoms of depression in adolescence predict future depression and increased suicide risk and are associated with a range of negative health outcomes (D. M. Fergusson, et al., 2005). Early interventions that target depressive symptoms are thought to be important in reducing the impact of those symptoms and in preventing the development of more



severe distress (Garber, 2006). Cognitive behavioural therapy (CBT) is the first treatment recommended for mild to moderate depression (National Institute for Health and Clinical Excellence, 2005). However, most adolescents who are depressed do not get access to treatment (Zachrisson, et al., 2006). Computerised CBT (cCBT) has been found to be effective for adults with depression (Andrews, et al., 2010; Richards & Richardson, 2012) and may provide greater access to therapy (Calear & Christensen, 2010). Recent research suggests that cCBT may also be effective for adolescents (Attwood, et al., 2011; Calear & Christensen, 2010; Merry, et al., 2012; Richardson, et al., 2010; Stallard, et al., 2011).

However, there are unanswered questions about cCBT. Adherence rates are heterogeneous and are often low (Calear & Christensen, 2010), which is at odds with reports of good user satisfaction with cCBT in trials. Computerised CBT programme features and the context in which they are used vary widely. Professionals have concerns about cCBT including whether it might reduce help seeking or therapeutic contact (Christensen, Reynolds, & Griffiths, 2011; Stallard, Richardson, et al., 2010). Little is known about consumers' views on these issues. User satisfaction with treatment options and outcomes is critical for ethical and practical reasons (Kaltenthaler, Sutcliffe, et al., 2008). User insights are valuable in understanding ways in which programmes can be improved (Doherty, et al., 2010; Oakley, et al., 2006). To date there has been little exploration of adolescents' experiences of cCBT for depression.

Rates of depression among adolescents in Alternative Education (AE) programmes for those excluded from mainstream education are approximately double the rates of depression among adolescents in mainstream school (Clark, et al., 2010; Denny, Clark, & Watson, 2004). Adolescents in AE and other alternative schools for educationally alienated students report responding to depression in harmful ways such as hurting themselves or others (T. Fleming, Dixon, & Merry, 2012), difficulty in gaining access to health care or emotional care (Clark, et al., 2011; Clark, et al., 2010) and a reluctance to ask adults for help (T. Fleming, et al., 2012). We carried out a small trial of a cCBT programme called 'SPARX' with adolescents in alternative schools for students alienated from mainstream education. There were high rates of uptake and completion of SPARX and those in the intervention group had significant reductions in depressive symptoms (T. Fleming, Dixon, Frampton, & Merry, 2011). In this analysis we aimed to explore trial participants' experiences of cCBT including reasons for completing the programme, what they liked about cCBT, their perceptions of its impact on their well-being and on help seeking and their views on how it might best be used. This was an exploratory study aiming to generate initial understandings which could be investigated further in future research.

## Methods

The data reported here were collected during the course of a pragmatic randomised controlled trial of immediate compared to delayed cCBT 'SPARX' with adolescents in five alternative schools in New Zealand. As a pragmatic trial (Thorpe, et al., 2009), cCBT was tested in conditions close to those in which each school would wish to use cCBT outside of a research setting. Accordingly, in four sites all students were invited to participate in the trial (opt out), while in one site students could nominate themselves or be suggested by a tutor (opt in). In total, there were 32 participants with symptoms of possible depression at baseline (raw score of over 30 on the Children's Depression Rating Scale Revised for brevity here described as '*with symptoms*') and 12 with no or minimal symptoms of depression (raw score of under 30 on this scale: '*without symptoms*'). Each site was an Alternative Education programme or other alternative schooling programme for 13-16 year olds excluded or at risk of being excluded from mainstream schooling and considered to have major behavioural difficulties in ordinary schools. Participants were invited to complete 1 or 2 modules of SPARX a week over weeks 1-5 (for those randomised to immediate intervention) or weeks 6-10 (delayed intervention). Psychological rating scales were administered at baseline and at weeks 5 and 10. The methods of this trial and the effectiveness for the participants with depressive symptoms have been reported previously (T. Fleming, et al., 2011). The data for this study were gathered post intervention via semi structured interviews and satisfaction questionnaires as described below.

### Participants

Interviews were completed with 39 participants (30 with symptoms); 38 participants completed the satisfaction question (one female with symptoms was missed, due to an administration error). Demographic characteristics for participants in interviews were: Male 24; Maori 15; Pacific Island 12; New Zealand European 10; Other 2. All were aged 13-16 years. Five students dropped out of the trial and were not available for interview. This was 3 males (1 with symptoms); 2 females (1 with symptoms). Reasons for drop out were: moved to another city (2 persons); changed to another course (1); couldn't be bothered (1); no reason given (1).

### Computerised CBT programme

SPARX has been described previously (T. Fleming, et al., 2011; Merry, et al., 2012); in brief it is a 3D interactive computerised CBT programme for adolescent depression which utilises features such as overt instruction, immersive narrative, social modelling and game play to enhance engagement and changes in thinking and behaviour (Dondlinger, 2007; Read & Shortell, 2011; Thompson, et al., 2010). It has 7 modules or 'levels'. Each level consists of direct instruction with a 'guide', followed by play-based learning and practice in a fantasy environment. The user then returns to the guide who reviews learning and sets homework or real world practice.

## **Measures**

A pen and paper self-report satisfaction questionnaire was developed with three sections. The first quantified participants' opinions on the usefulness of the programme on a 5 point Likert scale with response options from very useful to not at all useful. The second quantified satisfaction with aspects of the intervention as follows: it looks like a computer game; you can learn things by yourself at your own pace; it has video clips of celebrities; it is different from talking to a doctor/counsellor; it showed me things I didn't know; I could do it at school/centre/home; it comes with a notebook that I can keep; it is made for young people; it has a New Zealand look and feel. The final section covered details of levels completed and views on appeal to other young people.

The semi-structured interview explored experiences and views regarding the use of cCBT. Areas covered included: views on the programme overall; whether and how it was useful for the participant and what helped the participant to complete the amount of the programme that they had used. Secondly, the interview explored participants' views regarding the use of computer programmes to help other young people, including how computerised therapy might impact on help-seeking and whether it should be offered to all young people in alternative schools or just to those who were depressed.

Data relating to specific details of the SPARX programme were collected to allow programme improvements; however, the focus of this investigation was on overall experiences and views regarding cCBT, and these are reported here.

## **Procedure**

Interviews and questionnaires were completed at 5 weeks following baseline for participants randomised to immediate treatment and at 10 weeks for those in the delayed treatment group. Interviews took place in a private space at the participant's alternative school, except for one interview which took place by telephone. Interviews were facilitated by TF (a New Zealand European female PhD candidate with experience as a clinical social worker in youth health and youth mental health services). TF took notes while interviewing participants and checked the accuracy of notes with them at the time (consultation had indicated that this was more acceptable in this group than audio recording).

## **Analysis**

Questionnaire data were summarised and frequencies presented for those with and those without symptoms and the total sample; however, no statistical testing was planned due the exploratory aims of the study and the small sample size.

Analysis of open ended interview data was carried out using a general inductive approach (Thomas, 2006). Data were read with the research questions in mind; however, no a priori models were imposed. I (TF) read through all interview data both participant by participant and by interview question multiple times, in order to immerse myself in participants' responses. I re-read the data and

identified lower order units of meaning or themes. These were clustered with like units to create the higher order categories or domains. These did relate closely to the main areas of interview questions. Within each theme, subtopics and contradictory points of view were looked for and then themes were reviewed for redundancy and the identification of the essence of each category. A second researcher viewed the scripts and independently derived similar themes. Differences were resolved by consensus. Data were coded using these themes and quotes encapsulating themes were selected. Scripts were re-read throughout this process; to ensure that reporting remained true to the data.

Finally, themes were reviewed alongside quantitative findings and organised so that quantitative findings and themes exploring related issues appear side by side and follow a logical sequence.

## **Findings**

Data are presented under the domains identified in the inductive analysis. For clarity, these domains are grouped into those relating personal experiences of using cCBT and those relating to the use of cCBT for other young people. Under each domain, themes identified in the inductive analysis and related questionnaire data are reported. Quotes illustrating each theme are presented in Table 13.

### **Personal experience of cCBT:**

#### **Completion**

An overarching theme or domain of 'completion' was identified in interviews. This included two themes regarding what helped participants to complete the number of levels they had done on the cCBT programme. The first of these, "narrative", related to wanting to see what would happen in the cCBT programme. The second, "schooling environment", reflected ideas that the support of tutors or the lack of more interesting things to do promoted completion (Table 13).

Most participants reported that they had completed all 7 levels of SPARX (Table 14). Most of those who did not complete said that they had run out of time to do it, although one person said that they had wanted to get on with schoolwork and another had not got round to it.

#### **Overall responses**

There were two very common overall responses to cCBT. The first, "fun and helpful", reflected views that the programme was both fun and personally useful. The second, "entertaining", reflected comments that the programme was enjoyable. There were two other themes identified in terms of general responses to the programme: "it feels caring" reflected statements that participants experienced the programme or characters in it as caring or encouraging. "Limited in terms of gaming"

reflected feedback that the programme was boring or slow, particularly compared to commercial computer games (Table 13).

Questionnaire data confirmed that the majority of participants were positive about cCBT (Table 14). In the questionnaire, mean ratings for all aspects of the programme were close to or greater than 4 out of 5 (where 1 is 'didn't like' and 5 is 'really liked') and the mode score for all aspects was 5. The following aspects of the programme received the highest mean scores: "I could do it at home"; "it looks like a computer game"; "it has a New Zealand look and feel"; "it showed me things I didn't know".

### **Personal impact of cCBT**

Analysis of interview data revealed that most respondents experienced cCBT as helpful. Most related this to feeling calmer, less angry or fighting less. In fact few mentioned feeling down, sad or depressed. Thus an overarching theme of "it's more about anger than about depression" was identified; this permeated much of the discourse about the impact of SPARX.

There were seven specific themes regarding the personal impact of cCBT. Three were closely related, and together represented the majority of comments relating to the impact of SPARX. These all related to the concept of "it's more about anger than about depression" and were "calming down", "less anger and fighting" and "better relationships". Other less frequently expressed themes were: "it wasn't helpful", "improved mood", "reduced suicidality" and "improved problem solving" (Table 13).

Questionnaire data also suggested that cCBT was useful (Table 14).

### **Views on the use of cCBT for other young people:**

#### **Role for computerised therapy**

Participants were generally positive about the idea of computers to help people with feeling down. Many students discussed ways that cCBT was different from counselling. Qualitative analysis identified four themes which contrasted counselling and computer therapy. Three of these favoured cCBT: "I don't like to talk/counselling can be too much", "you have more control with cCBT" and "it's easy to learn from". In contrast, a minority of participants stressed the limitations of computerised therapy compared to the personal, flexible or intensive support available in face to face therapy.

Finally, there was a significant theme which came up in this domain but was also mentioned in other areas; this was a "need for varied approaches" reflecting a desire for a range of approaches to meet individual preferences and needs.

#### **Impact of cCBT on help seeking**

Most participants thought that doing SPARX would mean that young people were more likely, rather than less likely, to ask for help if they were feeling down. Two themes relating to help seeking were

identified: the first, “it smooths the way”, related to concepts that cCBT would make it easier to seek help or talk to adults because it provided words, demystified therapy or provided confidence. The second, less common, theme, “I don’t need/want therapy now”, reflected suggestions that cCBT might reduce help seeking, because help was no longer needed or because cCBT was experienced as preferable to counselling (Table 13).

### **Universal or individual use**

The majority of participants thought that cCBT should be offered to all young people in alternative schooling, not just to individuals who were seeking help or were identified as having difficulties. Comments relating to this domain divided into two main themes. The first, “everyone has down times”, reflected ideas that cCBT might be useful for everyone because many people feel down and cCBT would help with current or future difficulties. The second, “It’s too hard to target”, reflected views that students may not recognise that they are depressed, wouldn’t show others if they were feeling down, or wouldn’t want to be embarrassed in front of others. Other participants considered that cCBT would be boring if you were not depressed. Finally a theme which related closely to “need for varied approaches” was identified; this was “offer it (to everyone), but don’t force it” (Table 13).

**Table 13: Themes from interviews**

Overarching categories	Name of theme	Example quotes	Sex (F/M) <sup>1</sup>	Sx (Y/N) <sup>2</sup>	Levels <sup>3</sup>
Completion	Narrative	I would finish it – to see what the end was.	F/N/7		
		Even though you want help you might not come back. A counsellor is more compelling to come back to ‘cause they will call you/send you appointments. But I did come back because I want to see what happens.	M/Y/7		
		(Tutor) gave us time to go and do it which was good.	M/Y/7		
	Schooling environment	There are too many other things to do at home, you get distracted. Have it at school.	M/Y/7		
		It’s more entertaining than school work.	M/Y/6		
Overall responses	Fun and helpful	It was interesting. Some people will just play the game. Me, I learnt from the game. It was interesting and fun, you do learn from game stuff.	M/Y/7		
		I didn’t think I would enjoy it but actually I did. .. The guide was on to it... I liked choosing the character, flying on the eagle, shooting gnats... thoughts, feelings, actions I liked that. What the guide said was really useful.	F/Y/7		
		It was good. The adventures were fun... I liked the puzzles. It gave me things to do when I am in trouble, having troubles.	F/N/7		
		The Bird of Hope, flying, helping that lady, the shy one, yeah I learnt something from this.	M/Y/3		
	Entertaining	The characters were good, choosing your character, I liked the King of Gnats ‘cause he was mean, ugly.	M/Y/7		
		It was cool, I like games, I’m a games freak.	F/Y/6		
	It feels caring	It felt personal, you know, like he (guide) was talking to you, like you got to know him.	F/Y/7		
		The programme is like a counsellor. The programme does feel quite human.	M/Y/7		
		The Bird of Hope is encouraging, it’s like having someone next to you, by your side, it will be in my memory.	F/Y/7		
	Limited in terms of gaming	It wasn’t bad. Got a little boring at times with the guide. I liked it when you were doing challenging stuff.	M/Y/7		
		I play heaps of games, there is lots of actions, compared to other games SPARX is not great.	M/Y/7		
		A bit slow, I didn’t like the mouse clicking (instead of using arrows), a lot of walking.	M/N/7		
Personal impact of cCBT	It’s more about anger than about depression	I wasn’t depressed, I don’t get depressed, I just get angry and punch, fight. It kinda helped with that – I’ve improved my anger, I don’t argue around the house.	M/N/7		
		If you put a kid on a computer for half an hour they calm down.	M/N/7		
	Calming down	I don’t get so angry now. It calmed me down.	M/Y/3		

		My mood changed, attitude changed. I'm a bit calmer now. Getting into fights and trouble less.	F/Y/7
	Less anger and fighting	(I learnt) how to control anger. It's like a switch. Helps me stay out of the boys home 'cause I am not getting into trouble. I haven't been in a fight since it started.	M/N/7
		I was not really depressed at the beginning I was just angry, but it was still useful. I am not angry now... It has changed me, I don't hate now.	M/Y/7
		You should give it to people in prison – they'll stop killing each other.	M/N/7
	Better relationships	Now I am not fighting with my bro, and I'm not getting into other fights. Using the skills, not to always get what you want but to get somewhere in life. I don't feel like hitting him. I learnt to not use fighting to get what you want.	F/Y/7
		I've been dealing with family a lot better, all of the skills, they help.	M/Y/7
Personal impact of cCBT (continued)	It wasn't helpful	It didn't change my responses (to the mood questions each session), the graph was flat week after week – I have a counsellor now, which helps.	F/Y/6
		I didn't really need it. It is OK for people who are not depressed – but I had learnt similar stuff in previous courses and counselling so I didn't really need it.	M/N/7
		I know heaps of that stuff anyway but I don't use it.	M/Y/7
	Improved mood	Oh yeah, I used to get some of those Gnats (gloomy negative automatic thoughts) – but now I am all positive. I am thinking positive, thinking of all the good stuff that has happened to me.	M/Y/7
		After a session w SPARX it does rub off a bit, you feel more positive, the skills, so you feel more up – it just brings you up a bit. It helped me, in a situation where I feel down I just think about what the guide said 'cause it was really helpful.	F/Y/7
	Reduced suicidality	I've changed I realise it (suicide) is stupid, I don't think about death all the time.	M/Y/7
		I don't even think about suicide or self harm now.	F/Y/7
	Improved problem solving	I am more cheerful, cope better with problems, learnt to breathe when I am angry.	F/Y/6
		It changed how frustrated I was, so I could understand what was going on. I was understanding what it (SPARX) was saying to me and I was solving problems.	M/Y/7
Impact of cCBT on help seeking	It smooths the way	It might open your eyes so you think OK and go to a real person if you need to.	F/Y/7
		It gives you more confidence for talking to a counsellor.	M/N/7
		It gives you ideas about how to keep calm and tell about what you need.	M/Y/7
	I don't need/want therapy now	Maybe less [likely to seek help], 'cause it helps.	M/Y/7
		Maybe it pushed me away from going to see a counsellor, if people tell me to do things I kind of don't want to do them Now I have learnt this stuff, I have got it myself.	F/Y/7
		Less because doing it on the computer is better than talking to an adult about what you are going through.	F/Y/7



Role for computerised therapy	I don't like to talk/counselling can be too much	With a counsellor you have to explain yourself, talk, I don't like this. The computer programme doesn't have too many questions.	F/Y/5
		SPARX sort of cools you down. Counselling, like talking, is too intense.	M/N/7
		The computer game is more relaxing and more open. It's hard to talk to adults, too intense.	F/Y/7
		It can be awkward, people studying you in counselling, and it goes on too long.	M/N/7
		I prefer talking to mum or cCBT, the counsellor is too much.	F/Y/2
	You have more control with cCBT	SPARX tells you the info and lets you figure out how to do it. You have more control and more hands on.	F/Y/7
		It's less complicated than going to a counsellor and having to blurt out how you feel each week. You have more control. You can't just leave a counsellor that you don't like.	F/N/7
		I prefer the computer, you can go at your own pace.	M/Y/7
	It's easy to learn from	I like the shield [against depression], I was trying to remember that stuff. It helped.	F/Y/7
		I knew all that stuff from counselling, it was a recap, it was simple, put it in ways that you could comprehend, made you use the skills more	M/N/7
		Taking time out, slow breathing – that feels stupid the first time. Before I have been told about this but not shown. This makes it easy to learn.	M/N/7
	Therapeutically limited	Compared to personalised therapy it's not as focused – less effective.	M/Y/6
		You can tell a counsellor how you are feeling. The counsellor is more helpful. You have more options, not just picking from a few options.	F/Y/6
		If you have other problems the computer can't solve you need a counselor.	M/Y/7
		If the young person is really depressed this is not enough, but it clearly says so, so that is OK.	F/Y/7
	Need for varied approaches	It's good to have the computer programme, I'm more into it. It's easier than talking to a person. Kind of fun in a way. It's not fun going to a counsellor.	M/Y/7
I'm not into the whole computer thing, I prefer the counsellor. SPARX is just playing a game, and all this talking [in SPARX], I just want to skip it, didn't really read it.		F/Y/3	
If you have got heaps of problems the counsellor is good, but if it's little things playing the game is good.		M/Y/7	
It's good 'cause everyone has their own way of seeking advice – it is a different way. It offers an option that will suit some. There aren't any down sides, it's just another option you can take or leave.		F/Y/7	

Universal or individual use	Everyone has down times	Everyone, because they don't know what is coming their way.	M/Y/7
		Everyone, as lots of people are depressed.	F/N/7
		Everyone can be a bit depressed in their life and having troubles. Be good to teach before you get into that situation.	M/N/7
		Everyone, everyone has feelings.	M/Y/7
	It's too hard to target	Everyone, 'cause people in AE put up a strong barrier, they act all happy but it's different when they are home or alone.	F/Y/7
		Everyone, 'cause they might not know that they are depressed, cause they are holding it in and haven't told anyone. Everyone can do it and feel better.	M/Y/7
		Everyone, 'cause if I was feeling down it would be too embarrassing.	M/N/7
	It's boring if you are not depressed	I didn't really need it. It is OK for people who are not depressed – but I had learnt similar stuff in previous courses and counselling so I didn't really need it.	M/N/7
		It's good for kids who need it.	F/N/7
	Offer it [to everyone] but don't force it	Everyone, but if someone is depressed it won't help them unless they like that. It wouldn't help me.	F/Y/3
		Offer it to everyone but don't make everyone do it – just offer it to them, not all will like it.	F/Y/6

<sup>1</sup> Sex = participant sex (M = Male; F = Female); <sup>2</sup> Sx = Symptoms of possible depression (N = No/minimal symptoms; Y = raw score of over 30 on the Children's Depression Rating Scale Revised indicating symptoms of possible depression); <sup>3</sup> Levels = Number of levels of cCBT participant reported completing.

**Table 14: Questionnaire responses**

	Participants with symptoms of possible depression (n=29)		Participants without depressive symptoms (n=9)		Total (n = 38)	
	n	%	n	%	n	%
	Completed all 7 levels of SPARX	21	72.4	8	88.9	29
SPARX was useful or very useful for them	25	86.2	8	88.9	33	86.8
Would recommend it to a friend	25	86.2	8	88.9	33	86.8

## Discussion

This paper presents the perspectives of adolescents who participated in a trial of cCBT in alternative schooling programmes. This group of mainly Maori and Pacific Island 13-16 year olds had valuable insights into the experience of using cCBT and how it might be best used for other young people. As this is an exploratory study with low numbers we did not test differences between participants with and without symptoms of possible depression; however, we have reported findings for each of these groups and generally they were similar. Overall most participants, both those with and those without symptoms, completed the cCBT programme, found it enjoyable and thought it helped them. Participants were positive about the idea of computerised therapy for young people and many compared it favourably to counselling. Many participants considered that doing cCBT made users more likely to seek help from adults. Generally participants thought that cCBT should be offered to all young people in alternative schooling programmes, although they also highlighted the need for young people to have choices in the treatment of depression.

There is only one previous publication which explores adolescents' views and experiences of cCBT for depression (Iloabachie, et al., 2011) and this does not focus on what enhances completion, the appeal of cCBT, or views of how it might be used. Hence the current findings are significant.

Participants considered that using cCBT in their alternative school and curiosity about what would happen in the programme helped them to complete cCBT. The former is consistent with previous research which has identified the importance of a structured context for adherence to cCBT (Neil, Batterham, Christensen, Bennett, & Griffiths, 2009). The latter is consistent with human-computer interaction research (Doherty, et al., 2010) and the field of serious gaming (Klopfer, et al., 2009), both of which have highlighted the importance of design features such as an immersive narrative to facilitate motivation in computer programmes. Programming features have received little attention in studies of cCBT to date. Rather, research has focused on the role of human support and encouragement. However, programme features are significant in user motivation (Dondlinger, 2007; Przybylski, et al., 2010) and should be considered in future research.

Our finding that participants thought the programme was useful and enjoyed it is consistent with the high satisfaction expressed in the few other trials of cCBT programmes for adolescent depression where this has been measured (Attwood, et al., 2011; Gerrits, et al., 2007; Iloabachie, et al., 2011; Merry, et al., 2012; Stallard, et al., 2011). The experience of interventions as effective by those that use them is critical for dissemination. Enjoyment is also important, and might enhance the impact of programmes as well as adherence to them (Przybylski, et al., 2010; Read & Shortell, 2011).

Interestingly, most participants reported that helpful effects of SPARX were increased calmness, reduced fighting and anger or improved relationships (often related to less anger). Comparatively few described feelings of reduced sadness or improved mood, although changes were accompanied by a drop in symptoms of possible depression (T. Fleming, et al., 2011). Irritability is an important feature of adolescent depression (Brent & Birmaher, 2002; Farmer, 2002) and adolescents in alternative schooling have high rates of behavioural difficulties (K. Johnson & Taliaferro, 2012; Murrihy, 2010). Feelings of anger and emotional dysregulation might be particularly salient to them. Whether treatments for depression in general, or SPARX in particular, can reduce aggressive behaviour in this group should be investigated further in future research: this would be an important finding.

Previous literature has suggested that therapists and others who work with young people are reluctant to use cCBT in part because of concerns that it might decrease help seeking or the use of human support (Christensen, et al., 2011; T Fleming & Merry, (in press); Stallard, Richardson, et al., 2010). In this study most participants thought the reverse might be the case. The possibility that cCBT might increase help seeking would also have important implications and should be tested.

Computerised CBT appears to be quite a different experience from face-to-face therapy. Our participants often expressed this as an advantage of cCBT. Their dissatisfaction with counselling deserves further investigation. That they found cCBT empowering is consistent with previous analyses of self-help and of cCBT (Iloabachie, et al., 2011; Khan, Bower, & Rogers, 2007). Their feedback that the computer was easy to learn from emphasises the importance of utilising the potential of the computer format. Interestingly, some participants experienced the cCBT programme as caring for them. In contrast, a minority of participants would have preferred counselling. Other studies of cCBT have also found that some users want more personal assistance (Bendelin et al., 2011; Gerhards et al., 2011; MacGregor, Hayward, Peck, & Wilkes, 2009). Together these studies highlight that cCBT is appealing to many, and that individual treatment preferences are important.

Our finding that most trial participants would prefer cCBT to be offered to all students in alternative schooling, whether they have depression or not, is interesting. Limited help seeking and stigma inhibit the uptake of cCBT by adolescents (Christensen, et al., 2011). Universal use, at least in high risk settings, could circumvent this. Rates of symptoms of possible depression were very high in this group, and even those without symptoms tended to find cCBT helpful. Thus offering cCBT to all students in settings of this nature might be reasonable. Previously we have found that SPARX did not cause harm (T. Fleming, et al., 2011; Merry, et al., 2012). However, there is an opportunity cost to running any programme and some students thought it was boring if one was not depressed. Opportunities to address this dilemma include the development of programmes which offer different modules dependent on individual needs, or programme enhancements to increase appeal.

## Strengths and limitations

This study utilises a small population group and a specific cCBT programme. Different groups and different programmes might yield different findings. Hence generalisability is limited. Adherence to the programme was measured by self report. The interviews were carried out by TF who was involved in programme design. While open and frank discussion was encouraged this may have led to a social desirability bias. However there is little research in this area and this group of young people is seldom considered. Therefore these findings are worthy of consideration but they should be regarded as exploratory.

## Conclusions

Most adolescents in alternative schooling programmes for students alienated from mainstream education found SPARX cCBT helpful, often because it made them feel calmer or less angry. Most considered that it might increase help seeking and thought it should be offered to all young people in alternative schooling, whether or not they had symptoms of depression.

Young people who are excluded from mainstream education have important insights and can contribute significantly to understandings of how to address their mental health needs. User voices are important in the development of cCBT and should be considered further.

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## **Part 2: Parent and alternative schooling providers feedback on the use of SPARX'**

This section is written in the style of a brief report but has not been submitted for publication.

### **Abstract**

**Aims:** To report parent/caregiver ('parent') and alternative school tutor, teacher or other staff member ('provider') feedback on the use of the 'SPARX' computerised cognitive behavioural therapy (cCBT) with adolescents in alternative schooling programmes for 13-16 year olds alienated from mainstream education. **Methods:** Brief semi-structured interviews with 10 parents of adolescents who had taken part in a trial of SPARX, and with all 5 providers who oversaw the trial of SPARX in alternative schools. **Results:** Parents and providers reported that cCBT was beneficial for young people. Some parents would have liked to be more involved in the therapy. The majority of providers considered the support provided to them by the researcher important for the implementation of cCBT. **Conclusions:** This small analysis suggests parents and providers can contribute to the dissemination of cCBT for adolescents in alternative schooling. Their feedback is important for identifying effective ways to do this.

### **Introduction**

Current research suggests cCBT for depression is generally effective for adolescents who use it; however, uptake of cCBT is often low outside of trials (Calear & Christensen, 2010). Little is known about how parents and schooling or youth work staff regard cCBT and yet they might be important in supporting the uptake and completion of it. Additionally, parents and staff who work closely with young people could support young people to integrate therapy into their everyday lives and might have insights which should be considered in the development or delivery of cCBT for adolescents.

This study took place as part of a larger programme exploring the use of cCBT ('SPARX') for young people alienated from mainstream education (T. Fleming, et al., 2011). In this study I aimed to report feedback from parents and providers on the use of SPARX.

## **Methods**

### **Parent interviews**

Brief semi-structured interviews were carried out with a total of 10 parents; they were parents or caregivers of five girls and five boys from 4 alternative schools. I facilitated interviews in a private space at the alternative school or by telephone. An interview guide was used (questions are listed in Table 15). Interviews took less than 10 minutes; written notes were taken at the time.

The sample of parents was obtained as follows: at post intervention interviews I asked young people with depressive symptoms at baseline if they would be happy for me [TF] to contact their parents to ask their views about SPARX. Three students did not agree (one had recently changed placement; two said they didn't talk about their schooling or their parents wouldn't have anything to say); one parent worked till at least 9pm each night; one didn't speak English; four had no telephone and four could not be contacted after four attempts. All 10 parents successfully contacted consented to participate. Once a diverse sample of parents had been interviewed and no new information was emerging in interviews no further interviews were sought.

### **Provider Interviews**

A brief (10-20 minute) semi-structured interview was carried out with the provider who oversaw the implementation of SPARX at each alternative school that participated in the trial. All five providers participated; 3 were female; 2 registered teachers; 3 tutors. Interviews were carried out by TF and took place at the alternative school (3), by telephone (1) or by email (1). An interview guide was used (questions are listed in Table 15), replies were written at the time and understandings were confirmed during interviews.

### **Data Analysis**

Data were analysed separately for parent and for provider interviews. In each case, data were read multiple times. For each question, responses were read carefully; units of meaning were identified and clustered with like units. The common element (category or theme) for each set of units was identified and labelled. Example quotes were selected. Secondly, units of meaning or themes that occurred across multiple research questions were identified. Scripts were re-read throughout the process to ensure that interpretation remained close to the data. A research fellow read all original data and independently identified similar common elements.

## Results

### Parent feedback

Almost all parents remembered that their young person was doing SPARX; few had questions about it (Table 15). Parents who did not recall that their son/daughter was doing SPARX reported that they had too many forms and notices to keep track of everything. Parents who had questions would have liked to have a look at SPARX (1 parent) or to check that their child had the skills to understand it (1 parent).

All parents thought there had been positive changes for their young person. Comments about positive changes fell into 3 categories: 'behavioural changes', 'improved mood' or 'limited changes' (Table 13). There were two categories of responses to the question of how SPARX could be improved. The most common was that there was no need for change, the programme was satisfactory. The second was that more information about the therapy for families, or more involvement of families would allow them to support the young person more effectively (Table 15).

**Table 15: Parent feedback**

Question	Categories or themes	Example quotes
Did you remember that [young person's name] was doing the SPARX programme?		
Do you have any questions about it (the SPARX programme)?		
Have you noticed any changes in [name] since doing the programme?	Behavioural changes	He's not so violent, aggressive. She's better, going back to school now.
	Improved mood	To me, yes, he's changed. He seems happier. Yes it was helpful for [name]; she seems to be doing quite well, quite positive at the moment.
	Limited changes	At first I did notice a few good changes, but like everything else it only lasts so long. He's been better – but still fighting with his [teenage] aunt who lives with us.
Is there anything you would like to suggest that could help improve how we do the programme?	It's fine as it is	No, the letter home said enough.
	Involve families	More info for parents, not just an information sheet but something like the SPARX notebook with what it's all about and how to help them, support them with it. Give parents a copy of the programme and notebook and talk it over with them

## Provider feedback

All providers considered that SPARX was beneficial for students and had few, if any, downsides (Table 16). Categories of responses to each research question are reported in Table 16. There was one overarching theme articulated repeatedly throughout the interviews with most of the providers. This was that cCBT was useful with the support of the researcher for staff. The researcher's support was expressed as important in terms of assisting with students' mental health needs (e.g. suggesting mental health referrals when safety issues were identified in assessments) and assisting with challenges in implementing cCBT (e.g. responding to computer problems, prompting students).

**Table 16: Provider interviews and feedback**

Question	Categories or themes	Example quotes
Where there benefits of running SPARX in your programme? (If yes, what were they?)	cCBT with mental health support was helpful	Absolutely, having the tool was excellent – but having you helping with it was good, someone with experience. Honestly, the feedback, info from you. Like when you had concerns and letting us know, 'cause we can't see it coming with all of them.
	There were side benefits	It was nice having something else; separate from me for them to do. ...and for our students it was helpful because it's a chance to learn how to use the computer.
Do you think SPARX has helped young people in your programme?	cCBT helped students	A lot of them spoke about the tools and things they learnt from it. Some kids gained a lot from it. Even if they had had previous counselling. Yes it got the young person thinking before acting, it helped manage their anger.
What were the downsides of running SPARX in your programme?	There were no downsides to cCBT, partly due to the researchers support	None at all. I don't think so, because of the regular visits. When the students had problems you were there within a week or so.
What do you think about the idea of a computer programme to help young people now?	Computers are a good way to engage young people	It's a media that the young people are gravitating to. Good for kids, it's part of their language, their repertoire, and what they understand. They got something from it because it was in their world view.
How realistic is it to use SPARX in a programme like yours? Are there things we need to be aware of if we were using it in other places?	cCBT is easy to use with support for the staff	There is nothing wrong with the way that you have run it. Someone coming in to run it is good, so it doesn't take you away from teaching. If we didn't have this, we'd probably still use it. It is user friendly. The support was great.

Would you want to run it again?	We'll keep using cCBT, particularly if we have support to do so	I'd like to run it again, for me any way to help our young people better themselves is great. Absolutely and intending to do so, but we do need a person (to support it) or professional development.
Suggestions for improvement/other comments	Offer cCBT as it was used in the trial	None – you are the man!

## Discussion

In this small study parents and providers considered that cCBT had been helpful for young people. Most parents had no questions or suggestions relating to cCBT but some thought that families could be more informed about the therapy and thence provide greater support for the young person. Providers thought that computers were a useful way to reach young people and didn't report any downsides to computerised therapy apart from the need for support in its implementation. Providers considered support from the researcher important for the use of the programme and many would wish to use it again, particularly if mental health support was available to them.

Parents have previously been reported to be positive about the idea of computerised therapy (Stallard, Velleman, et al., 2010); however, few studies have explicitly investigated parent satisfaction or comments on cCBT for young people and only Iloabachie et al. (2011) have explored parents' experiences with cCBT for depression. In that study, parents considered that cCBT ('CATCH-IT') was beneficial for their children and some wanted to participate more in the intervention so that they could provide more help to their child. My findings are consistent with these.

There has been very little research regarding the experiences of professionals supporting the use of cCBT by adolescents. Coyle et al. (2011) reported that 5 therapists utilising 'gNats Island' cCBT found it to be a useful adjunct to therapy and referring agencies were positive about the use of a cCBT programme for adults (MacGregor, et al., 2009). I was unable to find any literature reporting teachers', tutors' or other non-therapists' views or experiences of implementing cCBT for adolescents. Hence, these findings are new.

It is positive that providers considered cCBT helpful, as teachers and other service providers who are close to young people could potentially play a significant role in the dissemination of cCBT for students in alternative schooling and other settings and the satisfaction of those who implement programmes is important for dissemination (Aarons, et al., 2009).

Providers' experience that the computer was a good way to engage alternative schooling students in therapy is consistent with the views of the students themselves (Fleming and Merry, submitted). Providers identified no particular downsides of using computers as a medium for therapy. Previously,

therapists (Stallard, Richardson, et al., 2010), health clinicians (Gun, et al., 2011) and youth work service providers (T Fleming & Merry, (in press)) have been reported to have some concerns that cCBT might potentially have negative effects such as reducing human contact or help seeking. Such concerns were not expressed by providers here after using cCBT.

Our finding that most providers considered mental health support important for the implementation cCBT is interesting. Previous studies have reported that monitoring and follow up increases the completion of cCBT (Christensen, et al., 2009) and that monitoring and follow up can be provided by persons who are not mental health specialists (Cavanagh, et al., 2011; I. Marks & Cavanagh, 2009), although adequate training, support and supervision is required (Cavanagh, et al., 2011). Our findings suggest that alternative schooling providers can support their students to use cCBT, but that for most some assistance would be important. The feedback here suggests that the assistance provided in our pragmatic trial was satisfactory. This consisted of: ensuring that sites had adequate protocols for accessing help for young people who were severely distressed or suicidal; individual assessments of mood and safety pre and post intervention; assistance to make mental health service referrals if required; assistance when young people struck computer problems that the provider could not assist with; and, in the two sites where providers did not prompt or facilitate students going on the cCBT programme, weekly prompts to go on to the next level if the young person had not already done so. These factors were not considered part of the intervention that we were testing; it is salutary that they were considered so important by providers. Future research should consider the impact of the research process on how cCBT interventions are implemented and experienced in trials.

### **Strengths and limitations**

This is a very small study. Ten parents or caregivers participated. These were parents or caregivers of approximately 30% of the students who were depressed at baseline, and were limited to those whose children were happy for them to be contacted, spoke English and could be contacted by telephone. Only five providers were involved, although pleasingly this represents staff at 100% of our study sites. I [TF] carried out the interviews and was involved in the development of the cCBT resource, thus both social desirability bias and biased interpretation of results could be significant. To mitigate these risks, parents and teachers were invited to be open and frank; participants included teachers and parents of young people who had not enjoyed the programme and results were analysed with the support of another researcher; however, the risk of bias does remain. Interviews were brief. More in-depth interviews might have led to deeper understandings. Thus the current findings should be considered exploratory. They are of interest as there is very little research in this area and no previous research with parents or those who work with educationally excluded young people regarding experiences with cCBT.

## Conclusions

The findings from this small study suggest that parents and alternative schooling providers thought SPARX cCBT was beneficial for young people and they were prepared to support its use in alternative schools. Most providers would like mental health support for them to do this and some parents would like to be more informed or involved in cCBT so that they can support their children to use it. Parents and providers can contribute to the dissemination of cCBT for educationally excluded young people. Their input is important for identifying effective ways to do this.

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## Chapter 9: Discussion

In this mixed methods, multistage research I aimed to identify the potential usefulness of cCBT for symptoms of depression among adolescents in alternative schooling programmes for those alienated from mainstream education. Adolescents in alternative schooling have high rates of depression and yet seldom receive evidence based treatments for it. There is a paucity of research about how to treat depression in this high needs group; there are no studies investigating the use of cCBT in this group and, indeed, few studies investigating the use of cCBT among adolescents in general. This was, then, an area where research was needed. As part of a team, I helped to develop a cCBT programme for depression ('SPARX') that was tailored for adolescents, utilised engaging programming features and was based on learning and therapeutic principles.

In the first component of this research I investigated the views of providers (youth workers, tutors and others who might be important in facilitating access to cCBT for adolescents alienated from mainstream education) on issues that might impact on the potential utilisation of cCBT through their services. I identified that providers did consider supporting the emotional needs of their clients to be part of their role and, although levels of enthusiasm varied, they were interested in using cCBT. Most would prefer to use cCBT in the context of their own caring relationships with young people without necessarily identifying them as being depressed and without needing to refer them to mental health providers. Many would prefer to do this with all adolescents in their programmes rather than with specific individuals. Providers' greatest concerns were related to cCBT potentially displacing contact with helping professionals.

As cCBT was potentially acceptable to providers, I began the second study. Here I aimed to consider issues that might impact on the need for and utilisation of cCBT from the perspective of adolescents in alternative schooling. I found that these adolescents recognised the concept of depression, considered that their peers respond to feeling depressed in harmful ways and were very unlikely to ask for help for feeling depressed. Participants were dismissive of models of care requiring them to seek help from health providers or involving referral to mental health services. In contrast, they were interested in the concept of computerised therapy and were willing to try this, particularly if it could be offered in ways that did not embarrass them or single them out as having problems. Like providers, many of the youth participants considered that offering cCBT to all young people in a particular setting would be more acceptable than targeting individuals with depression.

These two studies highlighted the importance of responding to depression in this group and provided support for the concept of cCBT as an acceptable way to deliver an intervention, particularly if it could

be offered in ways that did not require young people to ask for help nor separate them out as having problems. These studies paved the way for the third component of the research, the pragmatic randomised controlled trial of immediate compared to delayed SPARX cCBT among adolescents. In this study I showed that SPARX cCBT appeared to be effective for reducing symptoms of depression in this population. The trial also demonstrated that it was feasible and acceptable to deliver SPARX cCBT in alternative school settings.

In the final component of the research I interviewed participants in the trial, as well as a sample of parents or caregivers and alternative schooling providers, regarding their views on the usefulness of SPARX cCBT and how it might best be used or improved. Most adolescents considered the programme had helped them, especially with reducing anger and fighting or increasing calmness. Most considered that it should be implemented for all students in alternative schooling, not just those who were depressed. Parents/caregivers and providers were satisfied with cCBT, although providers generally found the support of the researcher important in implementing the programme.

## **Acceptability, Effectiveness and Feasibility**

The findings of the four studies described above have been discussed in the relevant chapters. The overall research programme was designed to investigate whether cCBT was useful for reducing depression among adolescents in alternative schooling. Acceptability, effectiveness and feasibility were established as the overall criteria for usefulness (Chapter 4). In this section I review what is known regarding each of these criteria from other literature and what is added by my studies' findings.

A summary of how each of my four studies contributes to the consideration of these overall criteria is included in Table 17. The combining of results from related analyses is appropriate in mixed methods research and allows for more nuanced or detailed answers than might be achieved by any one method alone (Creswell & Plano Clark, 2007; O'Cathain, et al., 2008).

**Table 17: The contribution of Studies 1, 2, 3 & 4 to the consideration of Acceptability, Effectiveness and Feasibility Criteria**

	<b>Study 1</b>	<b>Study 2</b>	<b>Study 3</b>	<b>Study 4</b>	<b>Overall</b>
	<b>Interviews and focus groups with providers</b>	<b>Focus groups with adolescents</b>	<b>Pragmatic Trial</b>	<b>Youth, parent and provider feedback</b>	
<b>Acceptability</b>	Providers were interested in cCBT with some specific questions or reservations	Adolescents were positive about cCBT	Uptake of cCBT was high, and drop out low	Adolescents, parents and providers were positive about cCBT	Acceptability was demonstrated
<b>Effectiveness</b>			Participants with symptoms had significantly reduced symptoms of possible depression post intervention vs. waitlist; gains maintained at follow up	Participants, parents and providers found cCBT helpful	SPARX promising for the treatment of symptoms of possible depression
<b>Feasibility</b>	Some would not wish to identify individuals with problems, some lack computers	Adolescents unlikely to seek help	Uptake and completion good in sites where implemented universally	Providers considered cCBT feasible with support provided to them by researcher	It was feasible to implement SPARX as used in the trial

## Acceptability

Previous studies have shown that cCBT for depression is seen as potentially helpful by health clinicians and mental health providers (Coyle, McGlade, Doherty, & O'Reilly, 2011; Gun, et al., 2011; MacLeod, et al., 2009; Stallard, Richardson, et al., 2010), with some reservations such as concerns about the lack of a therapeutic relationship (Stallard, Richardson, et al., 2010), concerns regarding safety (Stallard, Richardson, et al., 2010) and concerns about the appropriateness of computerised interventions for clients with complex or serious difficulties (Coyle, et al., 2011; Gun, et al., 2011). In the few studies which have sought professionals' feedback after being involved in trials of cCBT, therapists and clinicians have been positive about the experience (Coyle, et al., 2011; MacGregor, et al., 2009).

The current work adds to the research that youth work service providers also consider cCBT potentially helpful, although some have concerns similar to those expressed by health and mental health clinicians. This work also adds that providers involved in the trial of cCBT appeared to have been satisfied with it:

no sites pulled out of the trial and providers who oversaw the implementation of cCBT were positive about it.

Moderate to high acceptability of cCBT has been found among adults in the general public (Gun, et al., 2011); however, acceptability of cCBT to adolescents has seldom been investigated. Stallard, Velleman, et al. (2010) reported that 37 8-17 year olds attending child and adolescent mental health services were generally not enthusiastic about computerised therapy, with most preferring to be seen in a service like the one that they were attending. In contrast, Marko, Fogel, Mykerezzi, & Van Voorhees (2010) found that of 14-21 year olds enrolled in a trial of cCBT, most thought that an online depression prevention programme was an idea that made sense and that it could help them. Each of these studies involved adolescents who were receiving or were soon to receive non-cCBT or cCBT interventions.

The current research appears to be the first to consider the acceptability of cCBT to adolescents not already committed to a treatment for depression. This work adds that adolescents in alternative schooling displayed a very high level of enthusiasm towards cCBT.

Adolescents' satisfaction with cCBT has generally been good in the studies which have reported this (Attwood, et al., 2011; Gerrits, et al., 2007; Iloabachie, et al., 2011; Merry, et al., 2012; Stallard, et al., 2011). However, uptake of cCBT, satisfaction for participants who have not completed cCBT and reasons for drop out have seldom been reported (Christensen, et al., 2009; Kaltenthaler, Sutcliffe, et al., 2008; Waller & Gilbody, 2009).

The current work demonstrates that in alternative schools where cCBT was trialled universally, almost all students were willing to try it, few dropped out of the trial and, having used it, most students (including those who did not complete cCBT) were positive about the use of cCBT and suggested it should be offered to all students in courses like their own.

Acceptability of cCBT to parents has also seldom been considered. Stallard, Velleman, et al. (2010) found that the majority of parents of young people attending a CAMS services considered that computer programmes could help their children. Iloabachie et al. (2011) reported that parents of young people who had used cCBT were positive about it.

The current research suggests that cCBT may be acceptable to parents or caregivers of young people in alternative schooling; very few parents or caregivers did not consent to their child participating in the trial, none removed their child from the trial, and those interviewed after the trial were positive about cCBT.

This research, then, is one of the first studies of acceptability of cCBT among adolescents and parents and appears to be the first for youth work service providers. Overall, this research found that cCBT

was highly acceptable to adolescents in alternative schooling and was also acceptable to providers and parents.

## **Effectiveness**

Computerised CBT has been found to be effective for adults with depression (Andrews, et al., 2010; Richards & Richardson, 2012). Several cCBT programmes for adolescents with depression or symptoms of depression have been tested and two systematic reviews have concluded that there is early support for the effectiveness of cCBT for adolescent depression (Calear & Christensen, 2010; Richardson, et al., 2010), as discussed in Chapter 7.

Since the finalisation of Chapter 7, there have been three further publications of trials of cCBT for adolescent depression; two investigate 'Think, Feel, Do' (Attwood, et al., 2011; Stallard, et al., 2011) and the other tests SPARX (Merry, et al., 2012).

As described by Stallard et al. (2011), Think, Feel, Do is an interactive, multimedia CBT programme for anxiety and mood problems among children and adolescents. It consists of 6 modules and is delivered by CD-ROM with the support of a facilitator. The facilitator is present throughout the delivery of the programme and discusses and elaborates on the content of the programme with the user (Stallard, et al., 2011). The first trial (Stallard, et al., 2011) involved child and adolescent mental health service users with anxiety or mild to moderate depression. Six 11-14 year olds (one with primary symptoms of depression) completed Think, Feel, Do. Post intervention these young people had greater improvements in symptoms than those in the waitlist control group and satisfaction was good (Attwood, et al., 2011). The second publication (Attwood, et al., 2011) reports the findings of two exploratory studies. In the first, cCBT was provided as a universal intervention to thirteen 10-12 year old primary school boys who were randomised to cCBT or a computer gaming condition. Reductions in anxiety but not emotional difficulties were demonstrated in the cCBT group (n= 6) (Attwood, et al., 2011). In the second study, twelve 10-16 year olds identified by school nurses or teachers as having mild or moderate emotional problems participated in cCBT under the supervision of a nurse. Significant improvements in anxiety and depression were reported following the intervention (Attwood, et al., 2011). These studies provide encouraging but very preliminary results.

Merry et al. (2012) carried out a large randomised controlled non-inferiority trial of SPARX cCBT for adolescents with symptoms of depression. 187 12-19 year olds presenting to school guidance or to health providers were randomised to SPARX or treatment as usual. Post intervention effects were at least as good for SPARX as they were for treatment as usual and improvements were maintained at 3

month follow up. The trial demonstrated that SPARX cCBT is a potential treatment for adolescents with depressive symptoms in primary care.

Thus, as of April 2012, four different cCBT programmes for adolescent depression have been subjected to controlled trials and presented in peer reviewed publications: CATCH-IT (Van Voorhees, Fogel, Reinecke, et al., 2009; Van Voorhees et al., 2008), MoodGYM (Calear, Christensen, Mackinnon, Griffiths, & O'Kearney, 2009; O'Kearney, et al., 2006; O'Kearney, et al., 2009), Think, Feel, Do (Attwood, et al., 2011; Stallard, et al., 2011) and SPARX (Merry, et al., 2012), as well as an online therapist led programme (Gerrits, et al., 2007). Although to date no trials have been carried out by research groups not affiliated with the programme developers and few trials have had active control conditions or follow up assessments there is good indication that cCBT can be helpful for adolescent depression.

The current research adds that SPARX cCBT is promising for the treatment of depression among young people in alternative schooling. The feedback gained following the trial indicated that as well as effectiveness using rating scales, cCBT was also considered effective by adolescents who used it.

## **Feasibility**

Previous studies have demonstrated that cCBT for adolescents can be implemented in school classrooms (Calear, et al., 2009; O'Kearney, et al., 2006; O'Kearney, et al., 2009), school guidance settings (Merry, et al., 2012), primary health care (Merry, et al., 2012; Van Voorhees, et al., 2005; Van Voorhees, Fogel, Pomper, et al., 2009; Van Voorhees, Fogel, Reinecke, et al., 2009) and mental health services (Stallard, et al., 2011).

The current research demonstrates that it is feasible or practicable to implement cCBT in alternative schooling settings. In this study cCBT was implemented in ways providers thought they would use it outside of a trial, minimal exclusion criteria were used, and there was no large input of resources. Decommissioned computers (used computers that had no book value) were provided to some sites for students to use. This would require some organisation to do on a larger scale. However the computer specifications required to run the SPARX cCBT programme are low. The computers were gained quickly and no payment was required.

Young people were verbally prompted approximately once a week to complete a level of SPARX if they hadn't already done so. This was a brief verbal prompt provided during school time by the alternative schooling staff member or the researcher. I did not measure the time required for this. Previous studies have suggested input of just a few minutes per week might be sufficient (Williams & Martinez,

2008). My findings also suggest that where a provider already has a close relationship with a user, and is already in day to day contact with them, limited dedicated time may be required.

SPARX was implemented under the supervision of alternative schooling providers with the support of myself as the researcher. In post intervention interviews providers said that support with mental health problems and implementation of cCBT was useful and such assistance might be required for them to successfully implement cCBT outside of the research. This is an important limitation in terms of the feasibility of cCBT and suggests an important role for health or mental health services, or perhaps a dedicated cCBT team, in supporting the use of cCBT in any alternative schooling dissemination of cCBT.

In contrast to high uptake in the four sites where SPARX was used universally, uptake was minimal in the one site utilising a targeted approach in this study. As this method was only used in one site, it is not appropriate to make conclusions on the basis of this finding. However, it must be noted that we have not shown it to be feasible to use cCBT in an individually targeted manner in alternative schooling environments.

## **Summary**

The current research adds to the existing literature that SPARX cCBT appears to be acceptable, effective in reducing symptoms of possible depression, and feasible to implement in alternative schooling environments.

## **Comparison with other interventions for depression among adolescents in alternative schooling**

At the outset of this research I carried out a literature search and identified two evaluations of interventions to treat or prevent depression among adolescents in alternative schooling. One was a group CBT programme for adolescents with behavioural problems and symptoms of depression (Wignall, 2006); the other was a family, school, community intervention which reported limited detail regarding programme content and impact on depression (Carpenter-Aeby & Aeby, 2005).

I updated the search in March 2012 and identified two further studies of interventions for depression among adolescents in alternative schooling or alienated from mainstream education. One was a pilot study of group CBT for depression with 60 adolescents including 15 alternative high school students (Ruffolo & Fischer, 2009). In this study, depressive symptoms were significantly reduced immediately post intervention (compared to pre intervention); however, differences were



not maintained at 6 week follow up. The other publication (Malberg, 2008) described providing psychotherapeutic support for students in a Pupil Referral Unit; however, no formal evaluation was undertaken. A systematic review of non-school community based anxiety and depression prevention programmes also identified no studies in alternative schools for adolescents alienated from mainstream schooling (Christensen, Pallister, Smale, Hickie, & Calear, 2010).

In contrast, 16 studies of programmes for anger management and/or reducing aggression or substance abuse in alternative schools were reported during a similar time period (K. Johnson & Taliaferro, 2012; Murrihy, 2010).

In summary, since 1995 only group CBT programmes have been shown to be promising for depression among students in alternative schooling and these have only been investigated in two small, uncontrolled studies (Ruffolo & Fischer, 2009; Wignall, 2006). Interventions to reduce externalising behaviours have been more extensively investigated. The current research adds to these findings that cCBT appears to be a useful intervention for symptoms of depression among students in alternative schooling. Feedback gained in the current research also raises questions regarding whether SPARX cCBT might also be useful for anger and aggression.

## **Strengths and limitations**

As outlined in the introduction, this research utilises a post-positivist paradigm and is influenced by social work and youth health traditions. Empirical methods are valued and attention is paid to the context of the research, the importance of methods used and the value of multiple sources of information. The findings are discussed in terms of what they add to the largely empirical literature in the area of cCBT for adolescents. Other implications are briefly considered in the implications and questions for further research section later in this chapter. Broader issues such as the implications of using a health intervention paradigm or the marginalisation of groups of young people are beyond the scope of this research; however, I would like to acknowledge that these are important issues.

The strengths and limitations of the individual studies have been discussed in preceding chapters. Overall this research has a number of limitations.

I carried out all interviews and assessments and was also involved in the development of the SPARX cCBT programme. Although measures were taken to reduce social desirability bias and to minimize the possibility of biases in interpretations of results, this remains an important limitation.

Secondly, these are small studies involving specific populations and one particular cCBT programme; hence, generalisability of findings is limited.

The focus group and interview components were exploratory and were not designed to test hypotheses. The general inductive approach to analysis was appropriate to the research questions. However, grounded theory or narrative approaches would also be valuable and would potentially help develop theory and nuanced understandings in the area.

The trial included short term follow up only, was not blinded and utilised a waitlist rather than an active placebo control group. Hence, while it provides an indication that SPARX appears to be effective, these findings too should be regarded as exploratory and promising, rather than proof of effectiveness.

The SPARX cCBT programme and the standardised measures used were not designed for specifically for alternative schooling students. Efforts were made to ensure relevance and to ensure that challenges with literacy were not a barrier. However this may have been problematic for some students. Additionally, Participant Information Sheets and Consent Forms were written using fairly complex language. I discussed the content of the forms with participants, but in future research I would obtain consumer input on these and ensure that they did not require a high level of literacy.

Despite the limitations of this work, there are a number of strengths. The multi stage, mixed methods, multiple informants approach utilised was compatible with research aims. It allowed research to be carried out in a way that reflected the concerns and priorities of participants. It has put young people from frequently marginalised groups (Smith & Pitts, 2007) at the centre of the research and allowed their voices to be heard and their particular needs, wants and insights to be considered. The staged nature of the research provided participants with an opportunity to shape the research and may have contributed to good recruitment (Oakley, et al., 2006). Implementation research, which considers factors such as consumer preferences and stakeholder behavior, has not penetrated widely into mental health research (Landsverk, Brown, Rolls Reutz, Palinkas, & Horwitz, 2011); this research takes a step in that direction. The intervention was tested in 'real world', rather than artificial research conditions. The work was transparent regarding processes used, numbers of participants approached and satisfaction among those who did not complete the programme. The opportunities for participant feedback allowed unexpected findings to emerge.

This is the first research on the utility of cCBT for young people in alternative schooling. It is also the first research investigating the use of cCBT for mainly ethnic minority and indigenous young people, the first involving the use of cCBT for young people who are likely to have high rates of co-morbid behavioural problems, and the first involving cCBT for adolescents who are neither in mainstream education nor seeking help from health care providers. Computerised CBT is considered to potentially extend help to those who have limited access to evidence based therapies; thus, consideration of its use among those who have limited access to mental health care is essential. The current research does this for a particular high needs group.

Therefore the findings are worthy of consideration, but they should be regarded as preliminary and subject to further investigation.

## **Implications and questions for future research**

### **Clinical Implications**

This research highlights the importance of responding to the emotional needs of young people in alternative schooling. Participants' responses in many sections of the research suggested that they had significant emotional needs and neither expected nor sought help for these. It is important that health and other service providers do not only focus on behaviour problems, but also recognise symptoms of possible depression among these adolescents.

The findings suggest that interventions reliant on adolescents in alternative schooling seeking help or providers referring them to mental health services are unlikely to be successful and that alternatives to mental health services and counselling, or at least significant improvements to how mental health services and counseling are offered and/or perceived, are required.

Computerised CBT has been shown to be a promising approach in this research. Other options might also be useful but few have been investigated. The research has shown that cCBT can be facilitated through alternative schooling providers if they are provided with support for mental health and implementation challenges that may arise. The findings strongly suggest that if cCBT or other approaches are offered in alternative schools, students need to be able to use them without being identified as having a problem in front of others. Offering programmes to all students in this group, rather than only to those who are identified as having depression, should be considered.

### **Implications for other groups**

Adolescents in alternative schooling share some characteristics with other adolescents who are 'underserved' or considered 'hard to reach' by existing health services (National Research Council & Institute of Medicine, 2009; Newacheck, Hung, Park, Brindis, & Irwin, 2003), such as adolescents outside of any schooling (T. Fleming, 2006), adolescents who have low rates of literacy, low educational engagement or high rates of behavioural difficulties, and perhaps adolescents in youth justice systems (Garland, et al., 2001; Stevens, et al., 2005). Thus findings from this study may be generalisable to some of these groups. This should be tested in future research.

Additionally, although the current research does not include ethnic-specific analyses, most participants were Maori and Pacific Island young people. There is little research regarding the acceptability and

effectiveness of interventions within specific cultural groups in New Zealand and yet ethnic specific information is critical for addressing health disparities (Alcorn, 2011). Thus research to investigate whether cCBT is acceptable within broader Maori and Pacific communities would be valuable.

The use of cCBT programmes for adolescents with varying levels of severity of symptoms has seldom been investigated. Often, cCBT is recommended as a first option/first step for those with mild to moderate depression, while medication and face to face psychotherapies are recommended for those with severe disorders (Bower & Gilbody, 2005; Cavanagh, et al., 2006; Hetrick, et al., 2011; Learmonth, et al., 2008; Williams & Martinez, 2008), although there is evidence that cCBT is as useful for depressed adults in secondary mental health services as it is for those in the community (Richards & Richardson, 2012). I have tested SPARX with adolescents with symptoms of possible depression, few of whom may have had full depressive disorders. The findings might not be generalisable to more depressed young people. The role of cCBT for different levels of depression should be considered further (Learmonth, et al., 2008).

### ***Other research questions***

The research raises many questions for further investigation. One of the foremost is why an intervention for depression was apparently helpful for so many students in alternative schooling. As is usual in CBT, there were multiple components of SPARX, including: expression of warmth and hopefulness; information about depression and mood; skills for dealing with anger and other strong emotions; relaxation skills; problem solving; social skills and cognitive restructuring. The changes on rating scales indicated that SPARX reduced symptoms which could have been caused by depression. The feedback from students also indicated that it was helpful, particularly in reducing feelings of anger, getting into fights and difficulties in social relationships. Whether SPARX (or similar interventions) can indeed reduce aggressive behaviour for students in alternative schooling would be relatively simple to test and is an important area for future research.

Whether SPARX was helpful because it reduced depression often experienced as anger and frustration or whether it was helpful because it addressed other issues that were not actually part of a depressive syndrome is not currently clear. It would be helpful to investigate this; if the active elements are those which are not central to depression these could be enhanced to better meet those particular needs. Conversely, if SPARX is helpful because depression was a central issue for alternative schooling students this has implications for other programmes which seek to change behaviour in alternative schooling students.

However, distinguishing which difficulties are most central is complex. Rates of co-morbidity among alternative schooling students are high (Garland, et al., 2001; Murrihy, 2010; Wignall, 2006). Depression and externalizing and risk taking behaviours often co-occur (Polier, Vloet, Herpertz-Dahlmann, Laurens,

& Hodgins, 2012; Wolff & Ollendick, 2006) and can be reciprocally reinforcing (Lee & Stone). For some young people symptoms of depression precede the development of problem behaviour (Aro, 1994; Kosterman et al., 2010; Sheidow et al., 2008), while for others problem behaviour precedes the development of depression (Boylan, Vaillancourt, Boyle, & Szatmari, 2007; Brensilver, Negriff, Mennen, & Trickett, 2011). Alternative schooling students are a diverse group; students are likely to have faced different sets of challenges, and different components of SPARX may have been important to different students.

An alternative option to untangling which issues are central to groups of users is the development of personalisable cCBT programmes. Needs could be assessed with tools embedded in the programme, and individuals could then be offered particular sections. These might include health promotion or prevention focused sections, as well as ones tailored to treat particular problems. Such an approach might allow the programme to address personal needs while reducing the risk of making students look different to their peers and might also reduce any possible disadvantages of providing programmes to people who do not need them.

This possibility aside, given the preferences for using cCBT with all students in alternative schooling expressed in this study, the possible advantages and risks of such an approach deserve investigation. Universal use in high needs groups might significantly increase access to treatment among adolescents who are reluctant to seek help or be referred to mental health services. It is possible that universal use in high risk groups might also have a preventative effect; certainly many of the adolescents in our study thought so. Further study should investigate whether this is the case. Possible disadvantages of universal use should also be considered. For example, Haeffel (2010) reported that CBT might promote rumination among non depressed users; the question has also been raised whether unnecessary experiences of cCBT might 'spoil' users for future use (Christensen, et al., 2011) and there may be high opportunity costs to routine implementation of cCBT (such as reducing time for class work or displacing other interventions).

Providers and therapists are concerned that cCBT might decrease help seeking or human contact (Gun, et al., 2011; MacLeod, et al., 2009; Peck, 2010; Stallard, Richardson, et al., 2010). Whether this is the case, or whether cCBT might actually increase help-seeking, as many of our participants thought, should be tested. A computer game designed to support young people's mental health, 'Reach Out Central', did increase help seeking among users (Shandley, Austin, Klein, & Kyrios, 2010) and Christensen et al. (2011) have also identified the need for this question to be investigated.

A therapeutic relationship involving caring and warmth appears to be an important part of what makes psychotherapy work (Peck, 2010). Observing SPARX in use I have wondered whether what is offered by the therapeutic relationship might be achieved in other ways with cCBT: firstly, whether caring and

warmth can be provided by one person (here the alternative schooling provider), while psychotherapy is provided alongside, but separate from, that relationship (here via computer); secondly, whether experiences of caring and warmth can be provided within well constructed computer programmes themselves. Christensen et al. (2009) and others have raised this second possibility and some participants in my research suggested that it was indeed the case.

The amount and type of support required for the successful implementation of cCBT among adolescents have implications for dissemination. Computerised CBT for adults has repeatedly been identified as having greater effects when offered with some encouragement, support or prompts (Richards & Richardson, 2012). In a recent meta analysis, no difference was found whether the support was provided by clinicians or administrators (Richards & Richardson, 2012) and brief support, for example 37 minutes of non-clinician telephone support over an 8 week period (Titov et al., 2009), has been effective. There is little research regarding support required for adolescents. In this research, young people were provided with brief prompts, usually by the alternative schooling provider. Future studies should explore who can effectively support adolescents to use cCBT, the amount of time required to do this, and what assistance might be required for supporters. Computerised CBT was provided in this research with pre and post intervention and follow up assessments. These were not considered a part of the intervention and yet they offered individual attention and the opportunity to identify safety issues and reflect on the impact of the programme. If cCBT were to be disseminated outside of clinical settings the need for assessments of this nature should be considered. Families were interested in supporting cCBT; the question of how best to engage them and utilise their support also requires further attention.

New developments of computerised therapy might also be explored. Opportunities to further exploit the use of programming features (such as immersive narrative), opportunities to use new technological developments and social media, the use of new psychotherapies and the development of computerised therapy for other issues are all worthy of investigation.

Other research needs regarding cCBT for adolescents include the need for evaluations of cCBT programmes by researchers independent of the programme developers, investigating the long term impact of cCBT, cost benefit analyses and investigation of the role of individual preferences. Studies often find more positive results for an intervention if they are conducted by researchers with an interest in that approach (Tolin, 2010). The impact of SPARX has been reported to be maintained for three months (Merry, et al., 2012); however, investigation of the maintenance of benefits of cCBT over longer periods is warranted. Computerised CBT might have a positive cost-benefit ratio compared to other options if it can be used for large numbers of adolescents. However, programme development costs may be large and support costs should be considered. Our findings also suggest that the role of

individual preferences for computerised therapy or other approaches are important and should be considered in future research.

Finally, in my opinion, it would be useful to investigate whether the period when adolescents are in alternative schooling is potentially an important time to intervene. There has been little research into the developmental trajectory of young people who are in alternative schooling and the influence of experiences at this stage.

## **Conclusion**

Symptoms of possible depression are common and harmful among adolescents in alternative schooling. These young people are unlikely to seek help and report dissatisfaction with counseling and mental health services. Youth work service providers, including alternative schooling providers, wish to support the emotional needs of their clients, but without necessarily having to identify mental health issues or refer to mental health services. New approaches to meet the emotional needs of these students are required. Computerised CBT for symptoms of depression is acceptable to adolescents in alternative schooling and appears to be acceptable to their parents and to alternative schooling providers. Implementation in alternative schooling, at least where cCBT is used universally and some support is available for providers, appears to be feasible. SPARX cCBT shows promise as an effective intervention for symptoms of possible depression among adolescents in alternative schooling. Most participants reported it as having positive impacts such as reducing anger and fighting and most considered that it may increase help-seeking and would be helpful for all students in alternative schooling programmes.

Computerised CBT is a promising approach for addressing depression among young people in alternative schooling. The views of young people, parents and providers, in addition to randomised controlled trials, are valuable in mental health research.

# Appendices



## Appendix A: Types of registered school in New Zealand

State schools	
"Ordinary" State schools	Government funded primary, intermediate, middle, secondary and area/composite schools. The most common type of school in New Zealand.
Te kura kaupapa Māori	State schools where the teaching is in te reo Maori and is based on Maori culture and values.
State-integrated schools	Previously private schools which have become part of the state system. They may have a special character (such as philosophical or religious beliefs).
Special schools	State schools for children with special needs due to special talents, learning or behavioural issues.
Regional health schools	Schooling for students with significant health difficulties who can't attend their local school because they are in hospital, recovering, or gradually returning to school.
Teen parent units	Units attached to some secondary schools catering to students who are pregnant or raising a child and for whom it is impractical to attend a mainstream school.
Correspondence School	State school providing distance learning for students who: <ul style="list-style-type: none"> <li>- live a long way from their nearest school</li> <li>- have a medical condition</li> <li>- have special education needs</li> <li>- or meet gifted/talented criteria.</li> </ul>
Designated character schools	State schools with special aims, purposes and objectives to reflect particular values (e.g. religious beliefs or cultural values).
Other registered schools	
Independent (or private) schools	Non state schools. Governed by independent boards; may charge fees; receive some government funding; must meet specified standards.

Source – abridged from

<http://www.minedu.govt.nz/Parents/AllAges/EducationInNZ/SchoolsInNewZealand/SchoolTypes.aspx>

## Appendix B: Search Terms

### Search terms for cCBT for Adolescent Depression

1. computer\$.mp.
2. (on line or online).mp.
3. web.mp.
4. internet.mp.
5. exp Computer Applications/ or exp Computer Assisted Therapy
6. CBT.mp.
7. cognitive behav\$.mp.
8. exp Cognitive Behav\$ Therapy/
9. self help.mp.
10. exp depressive disorder/
11. affective symptoms/ or depression/
12. depress\$.mp.
13. dysthym\$.mp.
14. 1 or 2 or 3 or 4 or 5
15. 6 or 7 or 8 or 9
16. 10 or 11 or 12 or 13
17. 14 and 15 and 16
18. limit 17 to adolescent

### Search terms for depression interventions for adolescents in alternative schooling

1. Educational neglect.mp.
2. ((drop out\$ or dropout\$ or dropped) adj3 (school\$ or education\$)).mp.
3. (alternative adj3 (school\$ or education\$)).mp.
4. ((exclud\$ or alienat\$ or outside or suspend\$ or expel\$ or expul\$ or disaffect\$ or marginal\$) adj3 (school\$ or education\$ or student\$)).mp.
5. pupil referral unit\$.mp.
6. ((non traditional or nontraditional) adj3 (school\$ or education\$)).mp.
7. ((non mainstream or nonmainstream) adj3 (school\$ or education\$)).mp.
8. Student Dropouts/
9. (Emotional and behavi\$ difficult\$ units).mp.
10. special behav\$ schoo\$.mp.
11. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12. exp Depressive Disorder/
13. Affective symptoms/ or Depression/
12. Dysthymic Disorder/
15. (depressi\$ adj3 disorder\$).tw.
16. (depressi\$ adj3 episode\$).tw.
17. Subclinical depress\$.tw.
18. Sub-threshold depress\$.tw.
19. depress\$ mood.tw.
20. Dysthym\$.tw.
21. Depressive Disorder/ or Depressive Disorder, Major/
22. depress\$.tw.
23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
24. 11 AND 23
25. limit 24 to since 1995; child or adolescent; trials, studies, evaluations, reviews and meta analyses.

### Search terms for provider attitudes to cCBT

1. (provider\* or clinician\* or therapis\* or counsellor\* or counselor\*).mp. [mp=title, abstract, subject heading, heading word]
2. (computer\* adj3 therapy).mp. [mp=title, abstract, subject heading, heading word]
3. (e adj1 therapy).mp. [mp=title, abstract, subject heading, heading word]
4. exp Computer Applications/ or exp Computer Assisted Therapy/ or exp Cognitive Behavi\$ Therapy/
5. (attitud\* or acceptab\* or perspecti\* or belie\*).mp. [mp=title, abstract, subject heading, heading word]
6. 2 or 3 or 4
7. 1 and 5 and 6

## Appendix C: Interviews and Focus Groups, Description of Procedures

This appendix provides details of procedures used in focus groups and interviews that were not included in the peer reviewed articles due to space limitations and reporting standards in the field.

Firstly quality procedures important for demonstrating trustworthiness in inductive analyses are outlined; secondly procedures used in this research are described.

### Quality procedures

Procedures most applicable for assessing trustworthiness in general inductive analyses are peer debriefing, stakeholder checks and research audits as described by Lincoln and Guba (1985) (Thomas, 2006). Other procedures include consistency checks such as independent parallel coding (Thomas, 2006).

*Peer debriefing* is a process of critically reviewing the researcher's stance or posture to the data, identifying and reviewing their assumptions in relation to the participants, the topic and the findings, and critically reviewing their evolving analyses (Lincoln & Guba, 1985).

*Stakeholder checks* involve research participants or others who have an interest and possible insight in the area, checking and comment on raw data, on the interpretations made or the reporting of findings (Thomas, 2006).

*Research audits* involve reviewing and checking the raw data against findings & interpretations. Checking can be internal (checking by the researcher) or external (checking by an outside person or group) (Thomas, 2006).

*Consistency of coding* is often not reported in literature using general inductive analyses. Where it is, this is typically independent parallel coding (where a second coder is given the research question and raw data and independently identifies meaning in the data). In grounded theory (Strauss & Corbin, 1998), checks of consistency of coding of data into identified themes are important, and the percentage agreement between coders may be reported. However general inductive analyses utilise simpler coding processes (Thomas, 2006) and generate differing reporting requirements. No recent peer reviewed publications using general inductive analysis were identified that reported checks of consistency of coding of data or percentage of agreement between coders. Rather peer and stakeholder review were prioritised. This is consistent with the processes used in this research.

Procedures used and quality processes used for inductive analyses in this research are outlined for each study below.

## **Study 1**

Both focus groups and semi-structured interviews were used in Study 1 (youth service providers' attitudes towards cCBT). The use of these contrasting methods was useful in two ways. Firstly, the use of both methods allowed potentially differing information to be elucidated (focus groups allow participants to build on ideas and concepts expressed by others, while individual interviews may allow more personal disclosure and can avoid the silencing of minority views). Secondly, the opportunity for individual interviews appeared important for some busy providers and facilitated the high participation rates gained.

I carried out all focus groups and interviews.

Field notes were kept. As for the other studies carried out in this research, these were brief notes detailing logistics such as start and finish time, any arrivals or departures of participants, process issues such as points of significant agreement, disagreement or humour and ideas or questions for my own consideration. The use of field notes is advocated in inductive research (Quinn Patton, 2002). I utilized notes as a memory aide, a prompt for considering ideas and a check when I was interpreting transcripts.

Groups/interviews were audio recorded. Recordings were transcribed by a professional transcriber. Analyses were performed as described in Chapter 5.

The following quality processes were used in this study:

*Peer debriefing:* I reviewed the processes used, my assumptions, interpretations and evolving analyses with my PhD supervisors (each of whom have experience working with adolescents and working with providers of community youth services).

*Consistency:* A second researcher was asked to independently derive initial categories or themes from the raw data. I met with her to discuss the research questions and to ensure she was familiar with the process of identifying meaning using general inductive analysis. The researcher read 6 transcripts and drafted initial themes from this raw data. We reviewed our analyses together. There was one significant difference in interpretation. We agreed that she had a stronger impression of most participants being positive towards the idea of cCBT than I did. We carefully reviewed this difference against the raw data. The difference appeared to be in part due to particular transcripts that she had

been given, and in part due to my own interpretation. Subsequently I carefully reviewed the raw data and revised my interpretation accordingly.

*Stakeholder checks:* Participants were able to comment on their own transcripts. The draft categories and themes were reviewed with two participants who had a good overview of the sector. Additionally a key informant was sent the draft article and invited to comment on it.

*Research audits:* I carried out multiple reviews of the raw data as I developed the categories and themes. I reviewed the final draft against the entirety of the raw transcripts. My PhD supervisors reviewed the article as it was drafted and finalised.

## **Study 2**

Focus groups and brief self-report questionnaires were used in Study 2 (adolescents' views on depression, help seeking and cCBT). The rationale for these processes and the methods used are described in Chapter 6.

These groups were audio recorded and transcribed. The transcription required multiple checks of my field notes and the audio record, as participants often used slang or made statements with irony or humour which were not obvious in the written record.

The following quality processes were used in this study:

*Peer debriefing:* The functioning and findings of each group were reviewed with co-facilitators of the group. The processes used, my assumptions about the data and my analyses were also reviewed with my PhD supervisors (each of whom have relevant experience).

*Consistency:* Following derivation of initial categories and themes, 5 transcripts were reviewed by a research assistant. She was given the research questions and asked to independently identify key themes. Although different terms were used, this process identified the same overall themes.

*Stakeholder checks:* Analyses were discussed with a clinician and researcher with considerable experience working with young people in alternative schooling. Secondly, two Pacifica youth workers and one Maori clinician, who all worked in the area, were given transcripts to review and then we discussed the transcripts and the draft analysis. I asked these advisors to comment on the scripts overall and specifically identify if I may have missed any cultural issues. The advisors supported my interpretations of the findings (which were shared with them after their own views had been discussed). No missing issues were identified.

*Research audits:* I carried out multiple reviews of the raw data as I developed the categories and themes. I reviewed the final draft against the entirety of the raw transcripts. My PhD supervisors reviewed the draft and final article.

## **Study 4**

Individual semi structured interviews were used in Study 4 (adolescent, parent and provider feedback). Individual interviews were selected over focus groups as I wanted to explore individual's experiences of cCBT and whether it helped them/their young person/s. I considered that young people in particular would be more likely to disclose this personal information in a one to one context than in front of peers as embarrassment had been identified as a major issue in earlier parts of the research.

For parents, one-to-one interviews via telephone (rather than face to face) were selected as providing an opportunity for gaining family input while imposing minimal research burden. For providers, one to one face to face interviews were preferred; however one interview took place by telephone and one by email in order to minimise non-participation.

One to one interviews were not audio recorded. This was based on feedback following initial youth focus groups. Young people in those groups described use of audio recording in one-to-one interviews as somewhat threatening and opined that it would be off putting and perhaps feel a bit like a police interview. Instead I used a sheet of paper with my interview questions laid out clearly on it, and wrote participants answers on this. It is more usual to record and transcribe interviews as this gives an accurate record (Bryman, 2008), however there are challenges with recording. Recording can generate large amounts of data (Bryman, 2008) and may detract from developing a sense of deep understanding (Stake, 2010). Taking research notes allowed the interview to be slow, as I wrote and checked answers. Participants were able to look over the paper and see what I had written. It appeared to me that this encouraged reflection and perhaps a feeling of control by the participants. It is important to consider power relationships and control in research with 'marginalised communities' (Hurley, 2007; Smith & Pitts, 2007) and thus this seemed a reasonable process. However participants did agree to recording in other parts of the research, so it is possible that audio recording would have been acceptable to all or most participants.

The following quality processes were used in this study:

*Peer debriefing:* The process of interviews, my assumptions and analyses reviewed with my PhD supervisors.

*Consistency:* After I had completed my initial analyses all transcripts of youth interviews were reviewed by a post graduate research assistant with training in psychology. All transcripts of parent and provider interviews were read by a researcher with experience in doing inductive analyses. Each of these persons were briefed in the methods and research questions and were given uncoded copies of transcripts and asked to identify initial categories or themes. Following this I met with each of them to review themes identified and discuss them in comparison to my own. In each case the overall interpretations and major themes and categories were consistent.

*Stakeholder checks:* Findings, initial analyses and the final analyses for youth interviews were reviewed with Associate Professor Sally Merry, as an experienced child and adolescent psychiatrist, her views and insights were particularly helpful. I also reviewed findings with a teacher experienced in working with populations similar to that in my study. Findings from provider interviews were reviewed with a participant who is an experienced leader in the field.

*Research audits:* I carried out multiple reviews of the raw data as I developed the categories and themes. I reviewed the drafts against the entirety of the raw transcripts multiple times. My PhD supervisors reviewed the draft and final article and chapter.

## Appendix D: Psychometric rating scales used in the trial

### Primary outcome

The Children's Depression Rating Scale-Revised (CDRS-R) (Poznanski & Mokros, 1996) is a clinician-rated scale utilising observation and interview data. It has been shown to demonstrate good internal reliability, test-retest reliability and inter-rater reliability, and concurrent validity with other measures (S. Brooks & Kutcher, 2001; Mayes, et al., 2010; Myers & Winters, 2002). The CDRS-R has been widely used in clinical settings, it has been shown to have very good sensitivity to change in severity of symptoms in adolescents (S. Brooks & Kutcher, 2001; Mayes, et al., 2010) and is the most frequently used scale for assessing change in severity of symptoms in intervention studies (Mayes, et al., 2010). The CDRS-R includes ratings of impaired schoolwork; difficulty having fun; social withdrawal; disturbances of sleeping, eating and tiredness; physical complaints; irritability; excessive guilt; depressed feelings; crying; morbid and suicidal ideation; and observations of facial affect, speech and hypoactivity. As children's report of mood can be unreliable, this scale might be more sensitive to low mood than self report scales (Guo, et al., 2006). Conversely, as many included items are not specific to depression, the scale might over identify depression among adolescents with symptoms caused by other problems (Guo, et al., 2006).

### Secondary outcomes

**Reynolds Adolescent Depression Scale (RAD5-2)** (Reynolds, 2002) is a self-completed questionnaire assessing frequency of experiencing symptoms of depression and dysthymia. The earlier version, RAD5, which is almost identical, has been shown to have excellent internal reliability, construct validity and stability with adolescents (S. Brooks & Kutcher, 2001; Myers & Winters, 2002). Its reliability for NZ adolescents has been confirmed (Walker et al., 2005). The RAD5-2 has been widely used in community samples; hence, population norms are available. However, RAD5 includes little indication of the severity of symptoms (S. Brooks & Kutcher, 2001), its sensitivity and has not been well established in clinical samples and its ability to assess treatment effects is limited (Myers & Winters, 2002).

**Paediatric Quality of Life Enjoyment and Satisfaction Questionnaire (PQ-LES-Q)** (J. Endicott, et al., 2006) is a self-administered questionnaire designed to assess quality of life in children and adolescents.

**Spence Anxiety Scale** (S. H. Spence, et al., 2003) is a self-administered questionnaire designed to assess anxiety problems among children and young people. It has moderate reliability.

**Kazdin Hopelessness (HPLS)** (A. E. Kazdin, Rodgers, & Colbus, 1986) is a brief self report scale based on the Beck Hopelessness scale. It has good internal consistency and moderate reliability.

**Children's Nowicki-Strickland Internal-External Control Scale** is a child and adolescent self report scale of locus of control used in over 700 studies. Extensive sampling has indicated good internal consistency and reliability (Lindal & Venables, 1983; Nowicki & Duke, 1983; Nowicki & Strickland, 1973). The short form is used here.



## **Appendix E: Participant information sheets and consent forms**

## Participant Information Sheet

### C-CBT Depression programme for teenagers (adults views)

Hi, my name is Terry (Theresa) Fleming; I am a PhD student in the Department of Psychological Medicine, at the University of Auckland. I am working as part of a team on a computer programme which uses CBT (cognitive behavioural therapy) to help teenagers deal with low mood.

I would like to talk with you about this computer programme. I would like to show you the programme/ images from the programme, ask you about what you think about it and whether such a programme could be useful in your work.

#### *Background*

People are worried about how depressed teenagers can become. Research has shown that cognitive behavioural strategies may help teenagers deal with depression before it develops into a more serious problem. Those skills can be taught using interactive computer programmes. Two years ago we developed and piloted a prototype of such a programme with encouraging results and positive feedback.

#### *This project*

The Ministry of Health has given us funds to improve the game. We have run focus groups with a range of young people. We would also like to hear the views of providers of services to young people so that we can consider what is needed to make the programme practical to use in a range of settings.

#### *What would be involved?*

We will show you the programme / images from it and then will ask questions about what you think about the programme, whether such a programme could be useful for young people that you work with, and, if so, what kind of support might be needed to be able to do this safely. The interview will be less than one hour long.

#### *What if I chose not to participate or change my mind?*

Choosing whether you would like to take part is entirely up to you. You may choose not to take part or may withdraw from the discussion at any time and your employer has assured us that this will not affect your employment in any way. Although you may withdraw from the research at any time the information provided up to that point has to remain.

#### *What about confidentiality?*

Given the nature of a focus group, confidentiality can not be guaranteed. The interviews will be audio taped and the recordings will be transcribed. Staff members and the organisation that they work for will not be identified when we write up the results. All the identifying information will be securely stored at the Department of Psychological Medicine at the University of Auckland for six years and only the research team will have access to it.

#### *How is the project funded?*

The Ministry of Health has given us funds to improve the game. Terry Fleming's time is funded via a Bright Futures PhD scholarship.

*Terry (Theresa) Fleming*  
Researcher, PhD student  
Office: 3737599 ext 87891  
Email: t.fleming@auckland.ac.nz

*Dr Sally Merry*  
Principal investigator  
Office: 3737599 ext 86981  
Email: s.merry@auckland.ac.nz

*Prof Rob Kydd*  
HoD Psychological Medicine  
Office 3737999 ext  
Email: r.kydd@auckland.ac.nz

#### **Any ethical concerns?**

Contact: The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Room 005 Alfred Nathan House, 24 Princes Street, Private Bag 92019, Auckland. Tel: 3737599 ext. 83711.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPATION ETHICS COMMITTEE, 2008  
FOR A PERIOD OF 3 years FROM 19 11 2008 REFERENCE 2008/078



## Consent form

*This form will be held for a period of six years*

### C-CBT Depression programme for teenagers

Researcher: Theresa (Terry) Fleming, PhD student, Department of Psychological Medicine

I have read and understood the Information Sheet about the study designed to find out provider's views on the use of a computer programme for adolescents with depression. I have had a chance to ask questions and I know whom to contact if I want to know more. I have had time to consider whether I want to take part.

I understand that taking part in this study is voluntary (up to me) and that my manager has given the assurance that my choice to participate or not, or to withdraw from the focus group, will in no way affect my employment.

I understand that I may withdraw from the focus group at any time but that the information that I have provided up to that point will have to remain.

***I understand that no material that could identify me or my organization will be used in any reports on this study.***

***I wish to receive a copy of the results (please circle)                      YES    NO***

I \_\_\_\_\_(PRINT full name) consent to take part in this study

Signature:\_\_\_\_\_

Date \_\_\_\_\_

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPATION ETHICS COMMITTEE, 2008  
FOR A PERIOD OF 3 years FROM 19 11 2008 REFERENCE 2008/078

## Alternative Education (AE) Students Participant Information Sheet

**You are invited to be in a focus group about a computer programme to help young people.**

### **Background**

People are worried about teenagers who become depressed. Some strategies may help teenagers deal with feeling down. Those skills can be taught using interactive computer programmes. Two years ago we tested a basic computer game. The Ministry of Health has given us funds to improve the programme.

We would like to know what young people think about this programme. So we are running focus groups with young people.

### **What would be involved?**

We would like to invite you to a focus group. The group will take a maximum of 1 hour. As a thank you for your time and contribution to this project you will get a gift voucher for \$20.00.

### **What about confidentiality?**

Given the nature of the focus group, confidentiality cannot be guaranteed. You can withdraw from the discussion at any time but the information provided up to that point has to remain in the group. The interviews will be audiotaped and the recordings will be transcribed by someone who has signed a confidentiality agreement. You will not be able to be identified when we write up the results. All the identifying information about you will be kept under lock and key at the Department of Psychological Medicine at the University of Auckland for six years and only the research team will have access to it.

### **What if the discussion makes me feel upset?**

We hope that you will find the discussion fun. However, if during or after the discussion you feel worried or down, we would like you to let us or a staff member at your AE know and we will help you find appropriate support.

### **More questions?**

*We are happy to give you more information and answer questions. You can contact on the numbers below. We can arrange to see you at school if you'd like.*

<i>Dr Sally Merry</i>	<i>Karolina Stasiak</i>	<i>Theresa (Terry) Fleming</i>	<i>Prof Rob Kydd</i>
Principal investigator	Study Manager	Researcher, PhD student	Head
Office: 3737599 ext 86981	Office: 3737599 ext 83890	Office: 3737599 ext 87891	Dept of Psychological
Email: s.merry@auckland.ac.nz	Mob: 021 385677	Email:	Medicine
	Email: k.stasiak@auckland.ac.nz	t.fleming@auckland.ac.nz	Office 3737999

### **Any ethical concerns?**

**Contact: The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Room 005 Alfred Nathan House, 24 Princes Street, Private Bag 92019, Auckland. Tel: 3737599 extn. 83711**

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPATION ETHICS COMMITTEE ON  
Oct 08 FOR A PERIOD OF 3 years REFERENCE 2008/078



## Consent form

This form will be held for a period of six years

I have read and understood the information sheet about the study designed to find out young people’s views on the computer programme.

This study has been explained to me.

I understand what it is about.

I have had a chance to ask questions and I know whom to contact if I want to know more.

I have had time to think about whether I want to take part.

I understand that taking part in this study is voluntary (my choice) and that I can withdraw from the discussion at any time but that the information provided up to that point has to remain in the group.

I understand that confidentiality cannot be guaranteed but that no material that could identify me will be used in any reports on this study.

I wish to receive a copy of the results (please circle)                      YES    NO

I \_\_\_\_\_ (PRINT full name) consent to take part in this study

Signature: \_\_\_\_\_

Date \_\_\_\_\_

*Project explained by Terry Fleming 11 12 2008*

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPATION ETHICS COMMITTEE ON Sept 17 2008 FOR A PERIOD OF THREE YEARS, TO September 2011 REFERENCE 2008/078

Youth Focus Groups



## CEO/Principal /Board of Trustees

Your organisation is invited to take part in a study to see if using a computer programme called "SPARX" can help young people who are down, low or depressed.

### ***Background***

Lots of young people get depressed and most don't get help. Often depressed teenagers seem moody, angry, frustrated or disengaged from what is going on around them.

Research has shown that simple strategies can help teenagers when they feel down. These skills can be taught using interactive computer programmes.

Two years ago we ran a small study in which we tested a computer programme to help young people when they were feeling low. This worked well and young people gave us ideas on how to improve the programme.

Our new programme, called SPARX, is designed to an easy way to get some help with problems. We would like to test if SPARX can help young people with mild to moderate depression.

We are inviting young people to participate from a range of Alternative Education and Intensive Youth Work providers to participate. Participation in this study is voluntary, your organisation does not have to take part.

### ***What would be involved?***

We will work with you to refer students with signs of mild to moderate depression.

Each student would meet Terry Fleming (trained researcher) for a safety check and assessment of mood. Students who have mild to moderate depression & whose parents consent, will be invited to take participate in the study. If any of the students need more help than SPARX provides we will talk with you and help make sure the students get the help needed.

After this initial meeting students would be randomly allocated to group 1 – begin the SPARX programme now, or Group 2 – begin SPARX in approximately 5 weeks time. The SPARX programme consists of 7 modules of about 20- 30 mins each. These would usually be completed over a period of 4 weeks at the AE.

Terry Fleming will interview students again after approximately 5 weeks and 10 weeks, so that we can assess whether SPARX does help young people.

### ***Are there any risks to being in the study?***

We don't think that there will be any risks from part in the study and we hope that everyone who takes part will feel better at the end. All participants will be provided with contact details of people they can call if they need additional support during the study.

### ***Are there any benefits to being in the study?***

In general, people taking part in studies benefit from them, probably because of the extra help they get and the questions they are asked. In addition, research to date suggests that SPARX is likely to help young people.

### **What about confidentiality?**

All the information given to us will be confidential. Participants and organizations will not be able to be identified when we write up the results. All information about participants will be stored securely at the University and only the research team will have access to it.

However, if we are worried about the safety of a young person we will talk with you and make sure they get help. If necessary this will mean that their parent/caregiver is informed.

### **Will we hear about the results?**

Yes. If you are interested we will let you know what we have found from the study.

We will also publish the results in scientific journals and present the results at meetings and conferences. If SPARX is successful we are planning to make it freely available.

### **More questions?**

*We are happy to answer your questions. You can contact us on the numbers below.*

*Terry (Theresa) Fleming*  
Principal Investigator (PhD  
student)  
DDI: 9237891  
Mob: 021 2249 373  
Email:  
t.fleming@auckland.ac.nz

*Dr Sally Merry*  
Supervisor  
DDI: 923 6981  
Email: s.merry@auckland.ac.nz

*Grace Wang*  
Research Assistant  
Email:  
g.wang@auckland.ac.nz  
DDI: (64 9) 923 2015  
Fax: (64 9) 373 7013

*Prof Rob Kydd*  
Head  
Dept of  
Psychological  
Medicine  
Office 3737999

If you have any questions or concerns about young people's rights as a participant in this study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

This study is has been approved by the Northern Y regional ethics committee. Study reference number NTY/09/04/036

## **LOCALITY ASSESSMENT – by Locality Organisation**

Refer to pp10-12 of the Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project

**Full Project Title:** Youth e-therapy in Alternative Education and Youth Work Programmes: Evaluation of a computerised cognitive behavioural therapy (CCBT) Programme, for adolescents who have mild to moderate depression and are in Alternative Education or Intensive Youth Work Programmes.

**Short Project Title:** Youth e-therapy in AE and Youth Work Programmes

**Brief outline of study:** This study will investigate the efficacy of a computerised Cognitive Behavioural Therapy programme ‘SPARX’ for adolescents with mild to moderate depression. Study participants will be assessed prior to treatment, after a 6 to 8 week treatment period and again 3 months after completion of therapy.

**Principal Investigator:** Theresa Fleming.

**Contact details:** Department of Psychological Medicine, Faculty of Medical and Health Science, University of Auckland, Private Bag, 92019, Auckland; Ph (64 9) 3737599 ext 87891 or mobile 021 2249 373

**Supervisor:** Dr Sally Merry, Child and Adolescent Psychiatrist

**Supervisors Contact details:** Department of Psychological Medicine, Faculty of Medical and Health Science, University of Auckland, Private Bag, 92019, Auckland; Ph (64 9) 3737599 ext 86981

**Local investigator:**

**Contact details:**

### **Locality Organisation signoff**

Ethics committees review whether investigators have ensured their studies would meet established ethical standards, if conducted at appropriate localities; each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.

**Ethics approval for study conduct at each site is conditional on favourable locality assessment at that locality.**



**Locality issues: (see guidelines for more information and examples)**

**Identify any local issues and specify how they will be addressed.**

**Suitability of local researcher**

For example, are all roles for the investigator(s) at the local site appropriate (e.g. has any conflict the investigator might have between her or his local roles in research and in patient care been adequately resolved)?

**Answer:**

**1. Suitability of the local research environment**

For example, have the resources (other than funding which is conditional on ethical approval) and/or facilities that the study requires locally been identified? Are they appropriate and available?

**Answer:**

**2. What are the specific issues relating to the local community?**

For example, are there any cultural or other issues *specific* to this locality, or to participants for whom study recruitment or participation is primarily at this locality? If so, how have they been addressed?

**Answer:**

**3. Information sheet/consent form contact details:**

Contact details for Health & Disability Consumer Advocates:

Telephone :( NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

Contact details for any other important local services:

I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the Principal Investigator and then the relevant ethics committee should this occur.

**Signature:**

**Date:**

**Name:**

**Position:**

**Contact details:**

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## INFORMATION SHEET FOR PARENTS/GUARDIANS

We would like to invite your child to take part in a study to see if using a computer programme 'SPARX' can help young people with feeling down or depressed.

### *Background*

Lots of young people get depressed, down or find they are not enjoying life and feel angry lots of the time. Many young people get used to feeling like this and don't get any help. But there are things that can help young people change how they feel and have more good times again. One of the best ways to deal with these feelings is CBT - a kind of therapy called 'cognitive behavioural therapy'. At the University of Auckland we have developed a computer programme called SPARX, it is a mix of fun and CBT.

We would like to see if this is useful for young people. We would like your child to try it out and tell us what they think by answering questions before and after doing SPARX. Terry (Theresa) Fleming (PhD candidate at the University of Auckland) is running the study in AE and in Youth Work Programmes. Other researchers from the University of Auckland and Werry Centre are running studies of SPARX in schools and in health centres. The Ministry of Health has funded the development of SPARX.

### *How did we choose your child?*

We are inviting up to 30 young people in AE or Youth Work Programmes. Some but not all of these young people may be feeling down or depressed.

### *Does your child have to do this?*

No, no-one will mind if they don't do it. No reason has to be given

### *Can you change your mind later?*

If your child does take part they can leave the study at any time and don't need to say why. However the information given up to that point will need to stay in the study.

### *What would they be asked to do?*

- 1) Your child will be asked to take part in an interview.
- 2) If it seems like SPARX might be helpful for them then we will give this to them. They will be asked to do 2 levels of SPARX each week - either straight away or else beginning in about 5 weeks time. They can do it at their AE or Youth Work Programme. SPARX has seven levels and each take about 30 minutes to do.
- 3) We would then like to see them after 5 weeks and again after about 10 weeks to see how they are getting on and what they thought about SPARX.
- 4) If your child does take part we would like to contact you to ask you what you thought about 'SPARX' and whether you thought this was helpful.

When we first meet with your child, if it seems like SPARX is not for them, then we will help get other support if needed. If they are very depressed or suicidal we will make sure they are referred for mental health support.

For 1 in every 5 people who participate we will audio-record part of the interviews. These recordings would be used to get another researcher to check the interview is of good quality and has been done fairly. This other researcher will not know your child's name. After the interviews have been checked this recording will be destroyed.

### *Are there any risks to being in the study?*

We don't think that there will be any risks from taking part in the study. You and your child will be given contact numbers of people you can call and ways to get help if needed during the study.

### *Are there any benefits for being in the study?*

We hope that taking part will help teenagers feel happier, more able to solve problems and get on in their lives. Your child will be able to keep a copy of SPARX. As a thank you for their time they will be given a \$10 gift voucher for each of the 3 interviews that they complete with us.

### *Confidentiality: Does anyone else know what your child says?*

All the information given to us will be confidential and your child will not be identified when we write up the results. All information about them will be stored securely at the University and only the researchers directly involved in this study will have access to it.

A key staff member at your child's AE or Youth Work Programme will know that they are testing out SPARX.

We don't tell anyone what your child says when doing SPARX or talking to us EXCEPT if we are worried about them being very depressed or suicidal. If we are worried about this we will talk to the key worker at their AE or Youth Work Programme, or a GP or mental health service if needed. We would work hard to make sure you know what is happening too.

### *Will you hear about the results?*

Yes, we can let you know whether SPARX did help people if you would like. We will also publish the results and present the results at meetings.

### *More questions?*

*Feel free to contact us. We can come and see you if you'd like.*

Theresa (Terry) Fleming  
PhD candidate  
Phone: (09) 373 7599  
Ext: 87891  
Email: [t.fleming@auckland.ac.nz](mailto:t.fleming@auckland.ac.nz)

*Drs Sally Merry & Robyn Dixon*  
PhD Supervisors  
Phone: (09) 373 7599  
Ext: 86981(Sally) 87388 (Robyn)  
Email: [s.merry@auckland.ac.nz](mailto:s.merry@auckland.ac.nz)  
[r.dixon@auckland.ac.nz](mailto:r.dixon@auckland.ac.nz)

*Professor Rob Kydd*  
Head of Department  
Department of Psychological  
Medicine  
Phone: 373 7599  
Ext: 83774

If you have any questions or concerns about your child's rights as a participant in this study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone: (NZ wide) 0800 555 050 Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT) Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

### *Statement of Approval*

This study has received ethical approval from the Northern Y Regional Ethics Committee, which reviews regional studies (ref: NTY/09/04/036)



## PARTICIPANT INFORMATION SHEET (For Young People under 16 years)

We would like you to take part in a study to see if using a computer programme called SPARX can help young people with feeling down, angry or depressed.

### *Background*

Lots of young people feel down or find they are not enjoying life and feel angry lots of the time. Many young people get used to feeling like this and don't get any help.

But there are things that can help you change how you feel and have more good times again. One of the most powerful ways to do this is CBT - a kind of therapy called 'cognitive behavioural therapy'. We have developed a computer programme called SPARX, it is a mix of fun and CBT.

We would like to see if SPARX is useful for young people. We would like you to try it out and tell us if it is useful by talking with us and answering questions before and after doing SPARX.

Terry (Theresa) Fleming, PhD candidate from the University of Auckland, is running the study in AE and in Youth Work Programmes. Other researchers from the Werry Centre and University of Auckland are running studies of SPARX in schools and in health centres. The Ministry of Health has funded SPARX.

### *How did we choose you?*

Your AE or Youth Work Programme has agreed to ask people to take part.

### *Do you have to do this?*

No way, **taking part in this study is up to you**. You do not have to do it. No one will mind if you don't do it.

### *Can you change your mind later?*

Yes, **you can leave the study at any time**. You don't need to say why you leave, but the information you have given up to that point will need to stay in the study.

### *What would you be asked to do?*

- 1) You will be asked to take part in an interview.
- 2) If it seems like SPARX might be for you then we will give this to you, either straight away, or in about 5 weeks time. You will be asked to do 2 levels of SPARX each week. You can do it at your AE or somewhere else if you like. SPARX has seven levels and each take about 30 minutes to do.
- 3) After 5 weeks and again after about 10 weeks we will talk with you again and ask about what you thought of the programme and how you are feeling.

When we first met with you, if it seems like SPARX is not for you then we will help you get some other support if you need it.

For 1 in every 5 people who participate we will audio record part of the interviews. These recordings will be used to get another researcher to check the interview is of good quality and has been done fairly. This other researcher will not know your name. After the interviews have been checked this recording will be destroyed.

### *Are there any risks to being in the study?*

We don't think that there will be any risks from taking part in the study. You will be given contact numbers of people you can call and ways to get extra help if you need it during the study.

### *Why might you want to do it?*

We hope that taking part will be helpful for you. You will be able to keep a copy of SPARX. As a thank you for your time you will get a \$10 gift voucher for each of the interviews with us.

### *Confidentiality: Does anyone else know what you say?*

All the information you give us will be confidential and you will not be identified when we write up the results. All information about you will be stored securely at the University and only the researchers directly involved in this study will be able to see it.

A key worker at your AE or Youth Work Programme will know that you are testing out SPARX. Your parents/caregivers will need to know and agree to you doing SPARX.

We don't tell anyone what you say EXCEPT if we are worried about you being very depressed or suicidal. If we are worried we will talk to a key worker at your AE or Youth Work Programme, or if needed your parents/caregivers, GP or a mental health service to make sure you get help.

### *Will you hear about the results?*

Yes, we can let you know whether SPARX did help people. We will be writing and talking about whether SPARX works to other people too.

### *More questions?*

*Feel free to contact us. We can come and see you if you'd like.*

Theresa (Terry) Fleming  
PhD candidate  
Phone: (09) 373 7599  
Ext: 87891  
Email: [t.fleming@auckland.ac.nz](mailto:t.fleming@auckland.ac.nz)

*Drs Sally Merry & Robyn Dixon*  
PhD Supervisors  
Phone: (09) 373 7599  
Ext: 86981(Sally) 87388 (Robyn)  
Email: [s.merry@auckland.ac.nz](mailto:s.merry@auckland.ac.nz)  
[r.dixon@auckland.ac.nz](mailto:r.dixon@auckland.ac.nz)

*Professor Rob Kydd*  
Head of Department  
Department of Psychological  
Medicine  
Phone: 373 7599  
Ext: 83774

If you have any questions or concerns about your rights as a participant in this study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

### **Statement of Approval**

This study has been approved by the Northern Y regional ethics committee which reviews regional studies (Ref: **NTY/09/04/036**)



## PARTICIPANT INFORMATION SHEET (For Young People aged 16 or over)

We would like you to take part in a study to see if using a computer programme called SPARX can help young people with feeling down or depressed.

### *Background*

Lots of young people feel down or find they are not enjoying life and feel angry lots of the time. Many young people get used to feeling like this and don't get any help.

But there are things that can help you change how you feel and have more good times again. One of the most powerful ways to do this is CBT - a kind of therapy called 'cognitive behavioural therapy'. We have developed a computer programme called SPARX; it is a mix of fun and CBT.

We would like to see if SPARX is useful for young people. We would like you to try it out and tell us if it is useful by talking with us and answering questions before and after doing SPARX.

Terry (Theresa) Fleming, PhD candidate from the University of Auckland, is running the study in AE and in Youth Work Programmes. Other researchers from the Werry Centre and University of Auckland are running studies of SPARX in schools and in health centres. The Ministry of Health has funded SPARX.

### *How did we choose you?*

Your AE or Youth Work Programme has agreed to ask people to take part.

### *Do you have to do this?*

No way, **taking part in this study is up to you**. You do not have to do it. No one will mind if you don't do it.

### *Can you change your mind later?*

Yes, **you can leave the study at any time**. You don't need to say why you leave, but the information you have given up to that point will need to stay in the study.

### *What would you be asked to do?*

- 1) You will be asked to take part in an interview.
- 2) If it seems like SPARX might be for you then we will give this to you, either straight away, or in about 5 weeks time. You will be asked to do 2 levels of SPARX each week. You can do it at your AE or somewhere else if you like. SPARX has seven levels and each take about 30 minutes to do.
- 3) After 5 weeks and again after about 10 weeks we will talk with you again and ask about what you thought of the programme and how you are feeling.

When we first met with you, if it seems like SPARX is not for you then we will help you get some other support if you need it.

For 1 in every 5 people who participate we will audio record part of the interviews. These recordings would be used to get another researcher to check the interview is of good quality and has been done fairly. This other researcher will not know your name. After the interviews have been checked this recording will be destroyed.

### *Are there any risks to being in the study?*

We don't think that there will be any risks from taking part in the study. You will be given contact numbers of people you can call and ways to get extra help if you need it during the study.

### *Why might you want to do it?*

We hope that taking part will be helpful for you. You will be able to keep a copy of SPARX. As a thank you for your time you will get a \$10 gift voucher for of the three interviews with us.

### *Confidentiality: Does anyone else know what you say?*

All the information you give us will be confidential and you will not be identified when we write up the results. All information about you will be stored securely at the University and only the researchers directly involved in this study will be able to see it.

A key worker at your AE will know that you are testing out SPARX.

We suggest you tell your parents/caregivers that you are doing SPARX. If you do tell your parents/caregivers that you are doing SPARX and agree to us talking to them, then we will ask them what they thought about SPARX too. However you do not need to do this.

We don't tell anyone what you say EXCEPT if we are worried about you being very depressed or suicidal. If we are worried we will talk to a key worker at your AE Programme, or if needed, your GP or a mental health service to make sure you get help. We would always try to talk with you first of all.

### *Will you hear about the results?*

Yes, we can let you know whether SPARX did help people. We will be writing and talking about whether SPARX works to other people too.

### *More questions?*

*Feel free to contact us. We can come and see you if you'd like.*

Theresa (Terry) Fleming

PhD candidate

Phone: (09) 373 7599

Ext: 87891

Email: [t.fleming@auckland.ac.nz](mailto:t.fleming@auckland.ac.nz)

*Drs Sally Merry & Robyn Dixon*

PhD Supervisors

Phone: (09) 373 7599

Ext: 86981(Sally) 87388 (Robyn)

Email: [s.merry@auckland.ac.nz](mailto:s.merry@auckland.ac.nz)

[r.dixon@auckland.ac.nz](mailto:r.dixon@auckland.ac.nz)

*Professor Rob Kydd*

Head of Department

Department of Psychological  
Medicine

Phone: 373 7599 Ext: 83774

If you have any questions or concerns about your rights as a participant in this study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone: (NZ wide) 0800 555 050 Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT) Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

### **Statement of Approval**

This study has been approved by the Northern Y regional ethics committee which reviews regional studies (Ref: **NTY/09/04/036**)



## CONSENT FORM

*(For participants under the age of 16 and their parents/guardians)*

Project Title: Youth e-Therapy in Alternative Education  
and Youth Work Programmes Project

Principal Investigator: Theresa (Terry) Fleming (PhD Candidate),  
University of Auckland

I have read and I understand the information sheet for volunteers taking part in the study designed to test a computer programme for young people who are down or depressed. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau/family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is my choice (up to me) and that I may leave the study at any time and this will not affect my future health care or schooling.

I have had this project explained to me by my tutor/ teacher or a trained researcher.

I understand that my taking part in this study is confidential (private) and that nothing which could identify me will be used in any reports on this study.

I understand that the study will be stopped if it seems to be harming me.

I have had time to think about taking part.

I know who to talk to if I have any side effects or problems with the study.

I understand that if I become very depressed or suicidal Theresa Fleming or a researcher will talk to a key worker at my AE or youth work programme. If I am under 16 my parent(s)/legal guardian will be contacted and I will get extra help. This will include talking to a GP or mental health service if needed.



I would like the researcher to discuss the outcomes of the study with me      YES      NO

<b>For the parent/legal guardian (parent/guardian consent is required for all participants under 16 years of age)</b>	<b>For the young person:</b>
I _____ (full name ) hereby give my consent for my child _____ (child's full name) to take part in this study _____ Signature _____ Date	I _____ (full name ) agree to take part in this study _____ Signature _____ Date

\_\_\_\_\_  
Printed name of person obtaining informed consent

\_\_\_\_\_  
Signature of person obtaining informed consent

\_\_\_\_\_  
Date



## CONSENT FORM

*(For participants 16 years of age or above)*

Project Title: Youth e-Therapy in Alternative Education  
and Youth Work Programmes Project

Principal Investigator: Theresa (Terry) Fleming (PhD Candidate),  
University of Auckland

I have read and I understood the information sheet dated 15.7.09 for volunteers taking part in the study designed to test a computer programme for young people who are down or depressed. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau/family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is my choice (up to me) and that I may leave the study at any time and this will in no way affect my future health care or schooling.

I have had this project explained to me by Theresa Fleming or a trained researcher.

I understand that my participation in this study is confidential (private) and that nothing which could identify me will be used in any reports on this study.

I understand that the study will be stopped if it seems to be harming me.

I have had time to consider whether to take part.

I know who to talk to if I have any side effects or problems with the study.

I understand that if I become very depressed or suicidal Theresa Fleming or a researcher will talk to my tutor/teacher or youth worker and a GP or mental health service if needed.

*Please circle either Yes or No*

I would like the researcher to discuss the outcomes of the study with me      YES      NO

I agree to the researcher asking my parent/guardians to take part in a short interview about what they thought about 'SPARX'      YES      NO

---

I \_\_\_\_\_ (your full name )

give my consent (agree) to take part in this study

\_\_\_\_\_ Signature

\_\_\_\_\_ Date

---

Printed name of person obtaining informed consent

---

Signature of person obtaining informed consent

---

Date

## INFORMATION SHEET FOR PARENTS/GUARDIANS 30 3 09 Parent/Guardian Interviews

Your child is taking part in a study to see if using a computer programme 'SPARX' can help young people who have depression or are feeling down. When they complete SPARX we would like to contact you to ask what you thought about this.

We can meet up with you or talk to you over the phone. It would take about 15 minutes. We would like to ask you if you thought 'SPARX' was or wasn't helpful for your child, any problems or worries that you had about it and any suggestions you have for the future.

You do not have to take part. No-one will mind if you don't and it will not affect your child's participation in SPARX. If you do take part you can stop the interview at any time and don't need to say why. However the information given up to that point will need to stay in the study.

### *Confidentiality: Does anyone else know what you say?*

All the information given to us will be confidential you or your child will not be identified when we write up the results. All information about you will be stored securely at the University and only the researchers directly involved in this study will have access to it.

### *Are there any risks to being in the study?*

We don't think that there will be any risks from taking part in the study.

### *Are there any benefits for being in the study?*

We hope that this will allow you to ask any questions or give any feedback that you have about the study.

### **More questions?**

*Please contact us on the numbers below.*

Theresa (Terry) Fleming

PhD candidate

Phone: (09) 373 7599

Ext: 87891

Email: [t.fleming@auckland.ac.nz](mailto:t.fleming@auckland.ac.nz)

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### *Statement of Approval*

This study has received ethical approval from the Northern Y Regional Ethics Committee, which reviews regional studies (ref: NTY/09/04/036)



## Consent form (For Parents/Guardian Interviews)

I have read and I understand the information sheet dated 30.3.09 for parents/guardians taking part in the study to give feedback about 'SPARX'.

I have had the opportunity to use whanau/family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is my choice (up to me) and that I can stop the interview at any time and this will in no way affect my future health care.

I have had time to consider whether to take part.

I know who to contact if I have problems with the study.

I \_\_\_\_\_ (full name) give my consent (agree) to take part in this study

Signature: \_\_\_\_\_

Date \_\_\_\_\_

\_\_\_\_\_  
*Printed name of person obtaining informed consent*

\_\_\_\_\_  
*Signature of person obtaining informed consent*



## INFORMATION SHEET FOR KEY CONTACT PEOPLE 30 3 09

### Key contact person Interviews

Your AE/ Youth Work programme is taking part in a study to see if using a computer programme 'SPARX' can help young people who have depression or are feeling down. When the study is completed in your programme we would like to contact you to ask what you thought about SPARX.

We would like to ask you if you thought 'SPARX' was or wasn't useful, any problems or worries that you had about it and any suggestions you have for the future.

We can meet up with you where you work or talk to you over the phone. It would take about 15 minutes.

You do not have to take part. No-one will mind if you don't and it will not affect your student's ability to participate in SPARX. If you do take part you can stop the interview at any time and don't need to say why. However the information given up to that point will need to stay in the study.

#### *Confidentiality: Does anyone else know what you say?*

All the information given to us will be confidential and you, your programme or the young people in your programme will not be identified when we write up the results. All information about you will be stored securely at the University and only the researchers directly involved in this study will have access to it.

#### *Are there any risks to being in the study?*

We don't think that there will be any risks from taking part in the study.

#### *Are there any benefits for being in the study?*

We hope that this will allow you to ask any questions or give any feedback that you have about the study.

#### **More questions?**

*Please contact us on the numbers below.*

Theresa (Terry) Fleming

PhD candidate

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#### *Statement of Approval*

This study has received ethical approval from the Northern Y Regional Ethics Committee, which reviews regional studies (ref: NTY/09/04/036)



**Consent form**  
*(For Teacher, Tutor or Youth Worker Interviews)*

Project Title: Youth e-therapy in Alternative Education and Youth Work Programmes Project

Principal Investigator: Theresa (Terry) Fleming (PhD Candidate), University of Auckland

I have read and I understood the information sheet dated 30.3.09 for key contact workers taking part in the study to give feedback about 'SPARX'. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau/family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is my choice and that I may stop the interview at any time and this will in no way affect my future health care.

I have had this project explained to me by Theresa Fleming or a trained researcher.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have problems with the study.

I \_\_\_\_\_ (full name) give my consent (agree) to take part in this study

\_\_\_\_\_ Signature \_\_\_\_\_ Date

\_\_\_\_\_ *Printed name of person obtaining informed consent*

\_\_\_\_\_ Signature \_\_\_\_\_ Date

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