

# Northumbria Research Link

Citation: Gobrial, Ereny (2010) An exploration of management strategies for anxiety in children and young people with learning disabilities and autism. Doctoral thesis, Northumbria University.

This version was downloaded from Northumbria Research Link:  
<https://nrl.northumbria.ac.uk/id/eprint/2490/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

# **An exploration of management strategies for anxiety in children and young people with Learning Disabilities and Autism**

Ereny Gobrial

A thesis submitted in partial fulfilment  
of the requirements of the  
University of Northumbria at Newcastle  
for the degree of  
Doctor of Philosophy

Research undertaken in the  
School of Health, Community, and Education Studies

**October / 2009**

## ***ABSTRACT***

Although parents' involvement has been identified as important for interventions for their children and young people, little research is conducted to explore parental management strategies for anxiety in children and young people with mild to moderate learning disabilities (LD) and autism. Given that children and young people with LD and autism are more vulnerable to experience anxiety, the overall purpose of this thesis was to identify the prevalence rates of anxiety and explore management strategies for anxiety in children and young people with LD and autism.

Three studies were conducted to identify prevalence of anxiety and develop and implement a parental programme of management strategies for anxiety in children and young people with LD and autism. In the first study of this research "Screening study", 150 children and young people with LD and autism were screened for anxiety using Reiss Scale and Glasgow Anxiety Scale. Results from the screening indicated that children and young people with LD and autism have high prevalence rates of anxiety (32.6%). The second study of this research "Developing a programme" was to develop a programme of management strategies for anxiety from parents', carer's, teachers' and health professionals' views. In this study parents and teachers were interviewed regarding the management strategies they use to manage their children's / young people's anxiety. Results from 34 interviews revealed that sixteen different management strategies were identified by parents and teachers of children and young people with LD and autism. Following this, the management strategies identified by parents, carers and teachers were discussed with an expert panel of health professionals to develop a parental programme "Calm Child Programme" of the most useful and appropriate strategies for those children and young people. The Calm Child Programme was developed using Delphi method to identify a consensus approach with professionals. This consisted of ten useful management strategies for parents to manage their children's and young people's anxiety. Finally, the third study

of this research “Implementing the calm child programme” was a pilot study of the implementation for the Calm Child Programme. This programme of parental management strategies for anxiety was piloted with seven parents of children and young people with LD and autism. The results from the pilot study indicate reduction in the children’s and young people’s anxiety after its use by parents. Parents reported that the developed strategies were useful in managing their children’s and young people’s anxiety.

This research has two key contributions to knowledge. Firstly, this research highlighted the theme of anxiety of children and young people with LD and autism. The identification of high prevalence of anxiety in this population indicates the need for management strategies. Secondly, this research aimed to improve the paucity of autism specific research as it relates to anxiety management strategies in children and young people with autism. This research explored a new programme of parental management strategies for anxiety in children and young people with LD and autism. This research has contributed to our understanding of using systematic and evidence based management approaches in supporting and involving parents.

## TABLE OF CONTENTS

	<b>PAGE</b>
Abstract .....	II
Table of contents .....	IV
List of Appendices.....	IX
List of Tables .....	X
List of Figures .....	XII
Acknowledgments.....	XIII
Dedication .....	XV
Declaration .....	XVI
<b>CHAPTER 1: INRODUCTION.....</b>	<b>1</b>
1.1. Introduction.....	1
1.2. The rationale of the research.....	1
1.3. Aims of the Thesis .....	4
1.4. Overview of the Thesis .....	5
<b>CHAPTER 2: LITERATURE REVIEW .....</b>	<b>7</b>
2.1. Introduction .....	7
2.2. Literature search strategy .....	7
<b>SECTION I: LEARNING DISABILITIES, AUTISM, MENTAL HEALTH AND ANXIETY DISORDERS.....</b>	<b>9</b>
2.3. <b>Learning disabilities</b> .....	<b>9</b>
2.4. Historical issues.....	9
2.5. Terminology and definition .....	10
2.6. Classification .....	12
2.7. Prevalence .....	14
<b>2.8. Autism Spectrum Disorder .....</b>	<b>16</b>
2.9. Historical background .....	17
2.10. Definition and Classification.....	18
2.11. Diagnostic criteria.....	18
2.12. Nature of autism .....	20
2.13. Prevalence .....	23
2.14. Aetiology of autism.....	30

<b>2.15. Learning disabilities, autism and mental health .....</b>	<b>32</b>
2.16. Co-morbidity of LD and ASD .....	32
2.17. Prevalence of Mental Health in children with LD and autism .....	35
2.17.1. Learning disabilities and mental health problems .....	36
2.17.2. Autism and mental health problems .....	38
2.17.3. Comorbid learning disabilities, autism and mental health .....	39
<b>2.18. Anxiety in children and young people with learning disabilities and autism .....</b>	<b>42</b>
2.19. Diagnosis and Classification of anxiety .....	42
2.20. Prevalence of anxiety in learning disabilities and autism .....	43
2.20.1. Anxiety and Learning disabilities .....	43
2.20.2. Anxiety and autism.....	44
2.20.3. Anxiety in co-morbid LD and ASD .....	47
2.21. The manifestation of anxiety in LD and autism .....	48
2.22. Theories of autism and anxiety.....	50
2.22.1. Theory of Mind .....	50
2.22.2. The Central Coherence Theory.....	52
2.22.3. The Amygdala and anxiety .....	52
2.22.4. Social deficits .....	53
2.23. Assessment of anxiety and mental health problems .....	55
2.24. Policy and practice.....	60
<b>SECTION II: INTERVENTION / PARENTS PRESPECTIVES.....</b>	<b>65</b>
<b>2.25. Psychosocial intervention for anxiety in children with LD and autism .....</b>	<b>65</b>
2.25.1. Cognitive behaviour therapy .....	66
2.25.2. Behavioural therapy.....	70
<b>2.26. Parents' perspective and intervention .....</b>	<b>72</b>
2.26.1. Understanding nature of caring .....	72
2.26.2. Impact on the family.....	74
2.26.3. Impact of anxiety .....	76
<b>2.27. Involving parents in intervention.....</b>	<b>77</b>
2.28. Conclusion.....	86

<b>CHAPTER 3: METHODOLOGY .....</b>	<b>90</b>
3.1. Introduction.....	90
3.2. Methodological approaches.....	92
3.2.1. Methodologies with children with LD & autism .....	98
3.2.2. Methodologies in involving parents in interventions .....	99
3.3. Study design .....	101
3.4. Details of the studies .....	102
3.5. Participants .....	104
3.6. Measures and instruments .....	105
3.7. Data collection.....	106
3.8. Ethical consideration .....	107
3.9. Organizing and coding the data.....	109
3.10. Data analysis.....	110
3.11. Conclusion .....	111
<b>CHAPTER 4: SCREENING FOR ANXIETY.....</b>	<b>113</b>
4.1. Introduction.....	113
4.2. Method .....	113
4.2.1. Recruitment of participants .....	113
4.2.2. Participants.....	114
4.2.3. Measures and instruments .....	115
4.3. Data collection .....	121
4.3.1. Procedure for Reiss screening .....	121
4.3.2. Procedure for GAS-ID.....	122
4. 4. Data analysis.....	123
4. 5. Results .....	123
4.5.1. Reiss screen .....	123
4.5.2. GAS-ID screen.....	130
4.6. Conclusion .....	135
<b>CHAPTER 5: DEVELOPING CALM CHILD PROGRAMME .....</b>	<b>136</b>
5.1. Introduction .....	136
<b>5.2. PHASE 1: EXPLORATION OF INTERVENTION OF ANXIETY</b>	
<b>MANAGEMENT STRATEGIES.....</b>	<b>136</b>

5.2.1. Method.....	136
5.2.2. Recruitment of the participants.....	137
5.2.3. Participants .....	137
5.2.4. Measures and Instruments .....	138
5.2.5 Data collection .....	142
5.2.6. Data Analysis.....	143
5.2.7. Results 1: identifying strategies.....	151
<b>5.3. PHASE 2: DEVELOPING A PARENTAL PROGRAMME FOR ANXIETY MANAGEMENT.....</b>	<b>157</b>
5.3.1. Method.....	157
5.3.2. Delphi Technique .....	159
5.3.3. Recruitment of the expert panel .....	160
5.3.4. Participants .....	160
5.3.5. Procedure of Delphi Technique .....	161
5.3.6. Data Analysis.....	162
5.3.7. Results 2: developing a programme .....	163
5.4. Conclusion.....	172
<b>CHAPTER 6: IMPLEMENTING THE CALM CHILD PROGRAMME.....</b>	<b>174</b>
6.1. Introduction .....	174
6.2. Method .....	174
6.2.1. Recruitment of the participants.....	174
6.2.2. Participants .....	175
6.3. Measures and instruments.....	177
6.3.1. GAS-ID .....	177
6.3.2. Focus group. ....	177
6.4. Procedure .....	177
6.5. Data Analysis.....	181
6.6. Results.....	182
6.6.1. GAS-ID .....	182
6.6.2. Focus group.....	187
6.6.3. Evaluation of the programme.....	189
6.7. Conclusion.....	194

<b>CHAPTER 7: DISCUSSION .....</b>	<b>195</b>
7.1. Introduction .....	195
<b>7.2. STUDY 1: SCREENING FOR ANXIETY .....</b>	<b>198</b>
7.2.1. Prevalence of mental health .....	198
7.2.2. Prevalence of anxiety .....	200
7.2.3. Factors influencing high prevalence of anxiety.....	204
7.2.4. The importance of assessing and recognising anxiety.....	208
<b>7.3. STUDY 2: DEVELOPING CALM CHILD PROGRAMME .....</b>	<b>210</b>
7.3.1. Theme1: Antecedents of anxiety.....	211
7.3.2. Theme 2: Strategies used by parents and teachers.....	212
7.3.3. Theme 3: Management strategies.....	217
7.3.4. The need for a parental programme .....	217
7.3.5. The Calm Child Programme .....	218
<b>7.4. STUDY 3: IMPLEMENTING CALM CHILD PROGRAMMME .....</b>	<b>223</b>
7.4.1. Recommended refinements of the programme .....	229
<b>7.5. KEY ISSUES.....</b>	<b>233</b>
7.5.1. Anxiety in children and young people .....	236
7.5.2. Policy and practice.....	237
7.5.3. Involving and supporting parents in interventions .....	238
7.5.4. Policy and practice.....	238
7.6. Conclusion.....	240
<b>CHAPTER 8: CONCLUSION .....</b>	<b>243</b>
8.1. Introduction .....	243
8.2. Focus of this research.....	243
8.3. Implication and recommendation .....	245
8.4. Limitation .....	246
8.5. Implications for future research.....	248
8.6. Conclusion.....	250
<b>REFERENCES.....</b>	<b>253</b>

## LIST OF APPENDICES

Appendix – I	Ethical approval
Appendix - II	Ethical approval from university of Northumbria
Appendix - III	Title of electronic journal
Appendix - IV	Diagnostic Criteria for autism DSM-IV and ICD-1 0
Appendix - V	Invitation letter for parents 1
Appendix - VI	Young people information sheet
Appendix - VII	Consent Form
Appendix - VIII	Interview Schedule
Appendix - IX	Professional information
Appendix - X	Focus group Schedule
Appendix - XI	Reiss scales cut off scores
Appendix - XII	Calm Child Programme
Appendix - XIII	The parent’s invitation letter 2
Appendix - XIV	Parents information leaflet
Appendix - XVI	GAS-ID scale
Appendix - XVII	Visual time table
Appendix - XIX	Parent’s monitoring diary
Appendix - XX	Parent’s evaluation sheet

## LIST OF TABLES

		<b>PAGE</b>
Table 2. 1	Prevalence studies of autism spectrum disorders	26
Table 2.2	Prevalence studies of anxiety in children people with LD	44
Table 2.3	Prevalence studies of anxiety in people with autism	46
Table 2.4	Intervention studies for anxiety in people with LD	67
Table 2.5	Intervention studies for anxiety in people with autism	70
Table 4.1	Number of participants according to age groups and gender of the sample	115
Table 4.2	Summary of numbers of participants for Reiss and GAS-ID according to the age and gender for Reiss and GAS-ID	122
Table 4.3	Number of children and young people tested positive and negative for mental health problems using Reiss Scale	123
Table 4.4	Number and percentage of individuals tested positive on each Reiss scoring criterion	124
Table 4.5	Age groups (children / young people) and gender tested positive and negative for anxiety subscale on Reiss Scale	126
Table 4.6	Reiss (+ve MH & -ve MH problems), anxiety (-ve anxiety & +ve anxiety) Cross-tabulation	127
Table 4.7	Numbers and percentages of children and young people tested positive for anxiety and have other mental health problems	128
Table 4.8	Prevalence of anxiety subscale for Reiss Scale	129
Table 4.9	Case Processing Summary for Reiss anxiety and GAS-ID	130
Table 4.10	Reiss anxiety * GAS-ID Cross tabulation	130
Table 4.11	Frequency of age groups (children / young people) and gender tested positive for anxiety on GAS-ID scale	131
Table 4.12	Correlation between age, GAS, and GAS subscales (worries, fears and physiological symptoms)	133
Table 4.13	Means and standard deviation for GAS-ID anxiety scale across anxiety subscales and gender and age	134

Table 5.1	Numbers and percentage of participants	138
Table 5.2	<del>Table 5.2</del> management strategies among children and young people with LD and autism	
Table 5.3	Coding of categories / identification of management strategies	147
Table 5.4	Ranking of trigger factors for anxiety in children with autism and LD	151
Table 5.5	Rank orders in terms of number / percentage of management strategies used by parents and teachers	153
Table 5.6	Descriptive statistics for management strategies	154
Table 5.7	Percentage of management strategies that used according to the age group and factors that trigger anxiety	156
Table 5.8	The included and excluded strategies of the programme	163
Table 6.1	Characteristics of the children	176
Table 6.2	Results of Glasgow Anxiety Scale pre-and post-intervention	182
Table 6.3	Descriptive data for the study participants on GAS-ID scale	183
Table 6.4	Willcoxon Test Statistics	184
Table 7.1	Summary of Research Findings	197

## LIST OF FIGURES

	<b>PAGE</b>
Figure 3 (a) The study design	101
Figure 4 (a) Number of children and young people tested positive and negative for mental health problems using Reiss Scale	124
Figure 4 (b) Percentage of individuals tested positive on each scoring criteria for Reiss Scale	125
Figure 4 (c) Age group and gender scored positive and negative for anxiety on Reiss subscale	126
Figure 4 (d) Age groups (children / young people) and gender tested positive for anxiety on Reiss subscale	127
Figure 4 (e) Prevalence of anxiety subscale for Reiss Scale	129
Figure 4 (f) Age groups (children / young people) and gender tested positive for anxiety on GAS-ID scale	131
Figure 4 (g) Age groups (children / young people) tested positive for anxiety on GAS-ID scale	132
Figure 4 (h) Gender group (male / female) tested positive for anxiety on GAS-ID	132
Figure 5 (a) Theme 1: Antecedents of anxiety	145
Figure 5 (b) Theme 2: Management strategies	148
Figure 5 (c) Theme 3: Aims of strategies	150
Figure 5 (d) Descriptive statistics for management strategies	155
Figure 5 (e) Programme of Management strategies for anxiety	165
Figure 5 (f) Traffic light system	166
Figure 5 (g) Anxiety Scale Thermometer	169
Figure 5 (h) Example 1 Card numbers	170
Figure 5 (i) Example 2 Card pictures	170
Figure 6 (a) The anxiety scores pre and post programme	183
Figure 7 (a) Risk factors for anxiety in people with LD and autism	205

## **ACKNOWLEDEMENTS**

This research could not have occurred without the support of my supervisors who have provided timely and intelligent guidance at all points in my PhD research. My sincere thanks and gratitude is to my supervisor, Dr Raghu Raghavan, for his invaluable contribution. Who provided excellent guidance throughout the research, and who has always been on hand for guidance and advice. My sincere thanks extended to my second supervisor, Dr Joanna Reynolds who provided very useful insights during the completion and writing of this thesis. I am grateful to Professor Neil Small for guidance in design the research.

I am also indebted to Dr David Sims from CAMHs for his professional support, and I am also grateful to the health professionals team who working with him, who were involved in the study.

I owe my debt to the parents for the privilege of sharing their experience and debt to the teachers, who contributed their expertise and gave so generously of their time to this PhD research project.

I have also greatly appreciated the support provided by staff within the school and the autism support groups. I would like to thank the Head Teachers of all the schools where children recruited from. I also thank the autism support groups: National Autistic Society (NAS) Northeast and Contact a family, and other participated social groups in West Yorkshire for their help in collecting the data. I am grateful to Tony Machin, for help with the statistical analysis.

This project was made possible thanks to generous funding that I received from the Egyptian Government. This PhD research could not have been completed without this financial support.

Last, but certainly not least, I wish to thank my dear family, and friend for their never-ending support, help, understanding, encouragement, and dedication. I am extremely grateful to my husband, Aiman. You have been my support, my rock, my cheer leader and friend. My children, Steven and Menrit your encouragement and patience have been very important to me. Thanks for letting me finish the sentence or paragraph even when your questions needed to be answered immediately. My mum, I appreciate your kind support, and looking after my children. Thank you Aiman and thank you Steven, Menrit, and mum for enabling me to get the work done!

**DEDICATED TO**

My family

Aiman, Steven & Menrit and to the spirit of my Dad

Who continue to astonish me with their resilience, patience, and love

And

To all people with autism and learning disabilities

## DECLARATION

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. The work was done in collaboration with the School of Health, Community and Education Studies.

Name: ERENY GOBRIAL

Signature:  
Date:

# ***CHAPTER 1: INTRODUCTION***

## **1.1. INTRODUCTION**

Children and young people with learning disabilities (LD) are more likely to experience mental health problems such as anxiety than the general population. Similarly, children and young people with autism experience anxiety at a greater level than typically developing children (Gillott & Standen 2004; Kim et al. 2000). The co-morbidity with autism and LD is associated with an increased risk of mental health problems. The paucity of published research to date suggests people with comorbid LD and autism are more likely to experience mental health problems than people with LD but without autism, and they are more vulnerable to experience anxiety. Furthermore, co-morbidity specifically of autism may also make the children and young people with LD and autism more susceptible to anxiety. Despite this, there has been no published research focusing on the prevalence rates for anxiety in children and young people with mild to moderate LD and autism. Experiencing significant level of anxiety can have a devastating impact on the life of children & young people with LD and autism and their families. The purpose of this research was to identify the prevalence rates of anxiety and explore the management strategies for anxiety in children and young people with LD and autism.

## **1.2. THE RATIONALE OF THE RESEARCH**

There are several aspects to be taken into account when conducting research on developing and implementing parental management strategies for anxiety in children and young people with LD and autism. One key issue is the high prevalence rates of anxiety in these children. Research shows that the co-morbidity of LD and autism presents a significant mental health problem for this population (Morgan et al. 2003; Allington-Smith 2006;

Ghaziuddin 2000). Anxiety is one of the most common types of mental health problems in those children (Bradley et al. 2004; Hill and Furniss 2006; Brereton et al. 2006). It is suggested that people with autism experience anxiety at a greater level than general population (Bellini 2004 a; Kim et al. 2000; Holt et al. 2004). They are almost three-times more anxious than their non-autistic peers (Gillott & Standen 2004). Studies estimate prevalence rates of anxiety in individuals with autism range from 13.6% (Kim et al. 2000) to 84% (Muris et al. 1998). Moreover, as a group diagnosed with both disorders LD and autism, they demonstrated higher prevalence rates of anxiety compared to people with LD without autism (Bradley et al. 2004; Hill & Furniss 2006). It has been suggested that children with autism may be even more vulnerable to mental health problems such as anxiety because they may lack the appropriate coping strategies, as a consequence of social demands made upon them (Deudney & Shah 2004; Groden et al. 2001). They are more likely to experience life events associated with an increased risk for mental health problems than typically developing children (Brown 2000), particularly in late adolescents and early adulthood (Tantam & Perestwood 1999). Those children and young people are more vulnerable to experience anxiety as a result of the interplay between autistic and disability features, and other factors, for example low intellectual and communication ability, lack of social and cognitive resources and poor coping skills might affect the increased prevalence rates of anxiety (Cooray and Bakala 2005; Wilson 2004; Deudney and Shah 2004; Groden et al. 2001; Wilson et al. 2005). And they may have less effective resources than other youngsters for coping with adversity (Wilson et al. 2005). Although there have been much attention focused on the prevalence rates of mental health problems, very little has been published that assess the prevalence rates of anxiety in a group of children and young people with co-morbidity LD and autism.

Furthermore, anxiety severely impacts on the lives of children and young people with LD and autism and also their family carers (Kanne et al. 2009; Bradley et al. 2004; Eisenhower & Blacher 2006; Brereton et al. 2006; Grant et al. 1998). For instance, anxiety affects a child's interpersonal functioning,

as well as family functioning, and may seriously impair their life, and cause distress to their parents (Tehee et al. 2009; White and Hastings 2004). It may also impair their learning and opportunities for engagement with peers and other people (Rapee et al. 2008). Given the increased risk of developing anxiety in children and young people with LD and autism compared with their peers in the general population, it is important to focus on assessment and treatment of this anxiety. There is a need for support and development of effective management for anxiety, for instance parental management of anxiety of their son / daughter with LD and autism. This research aimed to screen for anxiety, develop and implement a programme of management strategies for parents of children with LD and autism.

Involving parents in this research is based on the idea that individuals are the best authority on their own lives, experiences, feelings and views (Stalker 1998). Research has suggested that parents of children with autism possess an experience-based or lived understanding of their children. Hence, they may be considered experts on their children. Together with their children, they take on the challenges of living with autism (Siegel 1997). Parents are more aware of the child's mental health and emotions. They face many difficulties and problems with their children, and parents may be stressed when their children experience difficulties. Involving parents has been found important in children's intervention. Parents are considered the child's most important resource and they have a vital role to play in providing the management and help that their child needs. Research evidence indicates that parental involvement in intervention is crucial for successful management of the interventions (e.g. Ozonoff and Cathcart 1998; Reavon and Hepburn 2003; Sofronoff and Attwood 2003; Reaven & Hupburn 2006; Diggle et al. 2008). Even though many studies have reported the importance of parent's involvement in implementing intervention strategies, there have no published studies that focussed on parental management strategies for anxiety in children and young people with LD and autism.

Given the substantial burden and the increased prevalence associated with anxiety and LD and autism for children and young people, and their families, there is a need to identify the prevalence of anxiety. There is a gap in the literature in assessing anxiety in children and young people with mild to moderate LD and autism. Additionally, given the importance of involving parents for supporting their children, and the fact that parental support has received little attention in the management of anxiety in children and young people with LD and autism, this research provides an overview of the prevalence of anxiety in this population and the development of a parental programme of anxiety management strategies. The development of a programme that supports parents managing their children's anxiety is a key theme of this research.

Many parents of children with LD and autism, and anxiety require more support to help their children manage the anxiety. This may be helpful to relieve parental stress and enhance family well being (Tehee et al. 2009; White and Hastings 2004). Parents' involvement in intervention is a preferred approach which is widely used in current practice (Diggle et al. 2008). The current research represents an attempt to develop and implement a programme of management strategies to support parents to help their children to manage the anxiety.

### **1.3. AIMS OF THE THESIS**

This research is conducted in three studies and this reflected in the objectives below:

1. To screen for mental health and anxiety amongst young people with LD and autism.
2. To identify everyday strategies that parents and teachers use to manage anxiety in children and young people with LD and autism.

3. To develop a programme of management strategies in managing anxiety for young people with LD and autism incorporating parents and health professionals' views.
4. To implement and evaluate the programme of management strategies with a small group of parents of young people with LD and autism.

#### **1.4. OVERVIEW OF THE THESIS**

**Chapter 2** reviews previous research that has investigated the anxiety in children and young people with LD and autism. It includes a description of the learning disabilities, autism disorders, and anxiety. The chapter is divided accordingly to two sections. Section- I is a brief discussion of LD, autism, and anxiety reviewing previous research that has concerned anxiety in children and young people with LD and autism. It explores theories of autism which explain relationships between anxiety and autism. Section-II considers the literature in relation to psychosocial interventions for anxiety in children with LD and autism, and also discusses the parent's perspective of caring for a child with autism.

**Chapter 3** addresses the aims and objectives, study design and methods of data collection. In addition, the ethical issues considered while conducting this research are reported in this chapter.

**Chapter 4** presents the method and the results of the screening study. The first study of this research is screening for anxiety among children with LD and autism. It describes two screening phases which were conducted to identify anxiety in children and young people aged 5 to 18 years.

**Chapter 5** includes a description of the methods and results of the second study of this research "developing Calm Child Programme" of management strategies for anxiety. There are two aspects to developing the programme of management strategies. The first is exploring and identifying the anxiety

management strategies through interviews with parents, carers and teachers. The second discusses the methods and results of Delphi technique to gain the expert panel of health professional's views in terms of the appropriate and effective strategies for anxiety in young people with LD and autism. In addition, the Calm Child Programme of anxiety management strategies was developed and this is discussed in detail.

**Chapter 6** describes the method and the results of the last stage of this research implementing the Calm Child Programme with parents caring for children and young people with LD and autism. It focuses also on the participant characteristics and the research procedures, data analysis and the results of implementing such a programme.

**Chapter 7** discusses the results of this research focusing on the three interlinked studies conducted for this research. This chapter addresses two specific key issues that have been raised from this thesis: anxiety in children with LD and autism, and involving and supporting parents in interventions.

**Finally, chapter 8** concludes the research results. The implementations and recommendations for further research are also considered in this chapter.

## ***CHAPTER 2: LITERATURE REVIEW***

### **2.1. INTRODUCTION**

This chapter reviews the literature related to learning disabilities (LD), autism, mental health and anxiety, and also reviews theories that have been proposed to describe anxiety representations in children with LD and autism. This chapter also explores interventions involving parents and subsequently considers anxiety in children and young people with LD and autism. This results in the conceptual framework for this research.

This chapter is divided into two sections. Section one includes discussion of learning disabilities and autism, and mental health problems. This section specifically reviews anxiety in children and young people with LD and autism. Section two addresses psychosocial interventions for anxiety and parental perspectives. This section discusses parental perspectives that have been studied in greater detail, focusing on parenting a child with autism, family stress and challenges in bringing up a child with autism. The essential role of parents' involvement in interventions is discussed.

### **2.2. LITERATURE SEARCH STRATEGY**

The databases MEDLINE, CINHALL and PsycINFO (1990 - 2009) were systematically searched. Terms of learning disability, "learning disabilities" or intellectual disabilities" or "mental retardation" or "mental handicap", were combined (and) with terms for autism: "developmental disability", "autism", or autism spectrum disorder" or "pervasive developmental disorder (PDD)" and with the term of "mental health problems", "psychiatric disorders", and combined with "anxiety". The search included only articles in English.

## **Hand search**

A further hand search was conducted searching the following journals for the last 10 years for articles relevant to interventions for anxiety, LD and autism: Journals of Intellectual Disability Research, Good Autism Practice; British Journal of Learning Disabilities and Psychiatric Bulletin.

The following search terms were used to identify articles of interest:

LD, autism, and anxiety

Assessment and diagnosis

Anxiety disorder and learning disability/ mental handicap

Anxiety and mental retardation

Anxiety and developmental disability

Anxiety and intellectual disability

Anxiety and autism /autism spectrum disorder

Anxiety and PDD

The literature review is organised using the themes of historical aspects of learning disability and autism, epidemiology of learning disability and autism, the nature and manifestation of anxiety, involving parents in interventions, management strategies and intervention for anxiety.

## **Search result**

A total of 450 articles deemed relevant and books were identified. A list of journals searched is formatted in Appendix (III).

## **SECTION I: LEARNING DISABILITIES, AUTISM, MENTAL HEALTH AND ANXIETY**

### **2.3. LEARNING DISABILITIES**

This section explores issues relating to the historical background, and then discusses the terminology and definition of learning disabilities, as well as the prevalence of people with learning disabilities.

### **2.4. HISTORICAL ISSUES**

During the middle of the 20<sup>th</sup> century, western countries saw a changeable pattern in the services for young people with LD as a result of deinstitutionalisation. In the past, a large number of people with learning disabilities lived in institutions, and were often segregated from mainstream community (DOH 2001). Then the White Paper “Better Services for the Mentally Handicapped” (1971) initiated the way for change when it set out an agenda for the next two decades that focused on reducing the number of places in hospitals and providing care in the community. The subsequent policies such as Care in the Community (National Health Service and Community Care Act 1990) have helped people with LD to live an ordinary life in the community. The White Paper valuing people (2001) promotes the importance of the attainment of ordinary lives for people with LD, through the key principles: rights, independence, choice, and inclusion (Department of Health 2001).

Following on from this, the United Nations Convention on the Rights of the child was ratified by the UK in 1991 and by Ireland in 1992. This encouraged the development of the services that put “children first” and were integrated with mainstream services (Royal College of Psychiatrist 2004).

As a result of the movement of children with LD from institutions to ordinary community settings, responsibilities for children were waived to parents at home and the Child and Adolescents Mental Health Service (CAMHs). Accordingly, parents became more responsible for their children when they faced difficulties and stress.

## **2.5. TERMINOLOGY AND DEFINITION**

The terminology of learning disability has varied over time. Before 1970, the term "mental sub-normality" was used (Department of Health 2001). Later on, in the 1980s, the World Health Organization defined the term "handicap". A handicap is the social disadvantage to an individual as a result of impairment or a disability (Mackenzie 2005). In the UK, mental handicap had become the common medical term, replacing the "mental sub-normality".

In the 1990s, the term "mental retardation" is used in both international classification systems: International Classification of Diseases (ICD-10) (WHO 1993) and Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR: APA 2000). The term "learning disabilities" was adopted by The Department of Health in the UK to identify the condition of mental retardation in 1991 (Department of Health 1995). Since that time "learning disabilities" has been predominantly used in the UK (The Royal College of psychiatrists 2004; Mackenzie 2005; Thomas and Woods 2003).

Other terms may be used to describe people with a learning disability. Intellectual disabilities and cognitive disability are synonyms for learning disabilities used in the USA (NCBDDD 2008), and the ICD-10 (World Health Organisation 1993), although "mental retardation" may also be found in older texts and USA-based resources (Northfield 2006).

There may be some confusion around the terms "learning disabilities" and "learning difficulties". This is due to use of different terms in different

parts of

the world, and a changing terminology over time (Raghavan and Patel 2005; Mackenzie 2005). General learning disability must be differentiated from specific learning difficulty. In the UK and USA "learning difficulties" refers to specific problems with learning in children (e.g. dyslexia) which means that the person has one difficulty, such as in reading, writing or understanding, but has no problem with learning in other areas (Raghavan and Patel 2005; Knight et al. 2006; Mackenzie 2005). The term "Developmental disabilities" is found mainly in the US, and can sometimes refer to a wider group, including people with acquired brain injury, or cerebral palsy (Northfield 2006).

The definitions for learning disabilities are broadly similar in the ICD-10 (WHO 1994) and DSM-IV-TR (APA 2000). Both definitions are based on the presence of impairments in adaptive function in association with low IQ, and to be presented during the developmental period (Grant et al. 2005).

The ICD-10 defines mental retardation as "a condition of arrested or incomplete development of mind, which is characterized by impairment of skills that manifest during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities" (WHO 1994).

The DSM-IV-TR, produced by the American Psychiatric Association (APA 2000), characterizes LD as "significantly sub-average general intellectual functioning, that is combined by significant limitations in adaptive functioning in at least two of the following skills: communication, self-care, home living, social / interpersonal skills, work, leisure, health and safety". The DSM-IV states that learning disabilities manifests itself before age 18 (APA 2000; PP. 41). The DSM also states that "there is no assumption that each category of mental disorder is a completely discrete entity with absolute boundaries dividing it from other mental disorders".

According to the Department of Health in England (2001), learning disabilities consists of the following:

1. A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
2. A reduced ability to cope independently (impaired social functioning);
3. Begins before adulthood, with a lasting effect on development.

The term "learning disabilities" will be used throughout this thesis instead of other synonyms because it is the term approved by the UK government, and because of its familiarity to parents, social services and professionals.

## 2.6. CLASSIFICATION

There are currently two widely established systems for classifying learning disabilities: the first classification system is that of the International Classification of Diseases (ICD-10 1993), which is produced by the World Health Organisation, and the second is Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR 2000) produced by the American Psychiatric Association (APA 2000). The ICD is the system used in the UK.

### u **ICD-10 (International Classification of Diseases) for Diagnostic Criteria for LD (WHO 1993)**

The ICD-10 defines each category of learning disabilities based on

#### **Level of learning disabilities (ICD-10) classification**

##### **IQ level**

<b>Borderline</b>	<b>70-90</b>
<b>Mild</b>	<b>50-69</b>
<b>Moderate</b>	<b>35-49</b>
<b>Severe</b>	<b>20-34</b>
<b>Profound</b>	<b>&lt; 20</b>

Intelligence Quotient (IQ), these are:

## u DSM IV- TR for Diagnostic Criteria for LD (2000):

According to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV), "mental retardation" (MR) or "learning disabilities" is characterized "by significantly sub-average intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning" (American Psychiatric Association 2000; PP. 41).

DSM-IV-TR subcategories differentiated by IQ scores (APA 2000) include:

- **Mild MR**                      **IQ Level 50-55 to approximately 70**
- **Moderate Retardation** **IQ Level 35-40 to 50-55**
- **Severe MR**                      **IQ Level 20-25 to 35-40**
- **Profound MR**                      **IQ Level Below 20 or 25**
- **MR, Severity**                      **Unspecified**

The dividing line between categories is given as a range because IQ scores may involve a measurement error of approximately 5 points. The concept of different degrees of severity of LD is almost universal in usage (Emerson et al. 1998). IQ scores are supposed to be unaffected by culture or language, but this assumption has been challenged. The DSM-IV and ICD-10 classifications are based on standardised IQ scores, although consideration should also be given to adaptive behaviour when making a judgement about the level of learning disabilities (Emerson et al. 1998).

According to the WHO (2000) the classification of LD consists of an interplay of factors, including both medical and social aspects. As it is a condition of incomplete development of the mind (IQ level < 70), it is associated with a diminished ability to adapt to the daily demands of the normal social environment.

## 2.7. PREVALNCE

According to the most recent estimates in the UK, the prevalence of people with learning disability is about 2% of the general population (Department of Health 2001; Facts and figures, Department of Health 2007). The estimated prevalence of children's mental health carried out by the Office of National Statistics in 2004 (Green et al. 2005) was consistent with the first national survey in 1999 (Meltzer 2000), revealing the same prevalence rates of children and young people with LD, 2% of the general population (Green et al. 2005). In the 2001 White Paper "Valuing People", The Department of Health (2001) reported that there are around 1.4 million people with learning disability in England. This figure comprised of approximately 1.2 million people with mild or moderate learning disability and 210,000 with a severe or profound learning disability.

The breakdown below gives an overview of the numbers of people with LD in England:

- There are an estimated 210,000 people with severe and profound learning disabilities in England: around 65,000 children and young people, along with 120,000 adults of working age and 25,000 older people (Department of Health 2001).
- In terms of people with mild / moderate LD, lower estimate suggested prevalence rate around 25 per 1000 population- some 1.2 million people in England (DoH 2001).
- Around 200 babies are born with a learning disability every week (MENCAP 2008).
- 700,000 disabled children under 16 in Great Britain (Department for Work and Pensions Family Resources Survey 2002-3).

Emerson and Hatton (2008) argue that it is not easy to produce reliable official statistics of the number of people with LD in the population (all these figures were broadly based on an assumed and predicted prevalence rates for people with LD in the general population) (Emerson and Hatton 2004, 2008). The variability and difficulty in identifying accurate prevalence rates can be understood as consequences of an interaction among several factors, including lack of data kept nationally on the numbers of people in England who have a LD (Emerson and Hatton 2004). As a result, any figures are based on those known to either health or social services and estimates in the general population, and not on a total population study. For example, only 20% of adults with LD are known to the learning disabilities services (Emerson et al. 2004). Another reason is the use of different methodologies, terminology and diagnostic criteria across studies and direct comparisons between those studies cannot be possible (Emerson and Hatton 2004; Raghavan and Patel 2005; MH-SIRG report 2001). It can be seen that it is often difficult to gain reliable information of the number of people with LD. Therefore, there is a lack of comprehensive data available on the exact prevalence of learning disability, and further research is desperately needed (Emerson and Hatton 2008).

There is evidence to suggest that all the projections show much higher prevalence rates in the number of people with LD in the UK over the coming years (Emerson and Hatton 2008). While the White Paper (Department of Health 2001) indicates that the number of people with severe LD may increase by around 1% per annum for the next 15 years, Emerson and Hatton (2004) predict that the total number of adults with a learning disability in England will increase by 8% in 2011 to 868,000, and by 14% in 2021 to 908,000 (from the 2001 figure of 800,000). This would raise the number of people with LD in England aged 15 and above to over one million in 2021 (ONS: Green et al. 2005).

The Department of Health (2001) illustrate some predicted interrelated factors which will contribute to an increased prevalence. These include:

- Increased life expectancy, especially among people with Down's syndrome;
- Growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood
- A sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities
- Greater prevalence among some minority ethnic populations of South Asian origin (Department of Health 2001; PP. 16).

It has been argued that the increased prevalence is as a result of demographic changes for the general population of England and the effects of reduced mortality among people with LD. And these changes are due to improved socioeconomic conditions, intensive neonatal care, and increasing survival (Emerson and Hatton 2004).

## **2.8. AUTISM SPECTRUM DISORDERS**

Autism Spectrum Disorders (ASD) is the name given to a set of neurodevelopmental disorders in which individuals are impaired in their social relatedness, in their ability to imagine, and in their ability to communicate (Wing 1996; APA 2000). Autism spectrum disorder usually becomes apparent before the age of 3 years (WHO 1992; APA 2000), and it is a lifelong developmental impairment (Brown et al. 2002). The majority of children with ASD have general cognition deficits consistent with LD (La Malfa et al. 2004; Hare et al. 2003; Morgan et al. 2002; Ghaziuddin 2000). It has been considered as one of the most common (MRC 2001), but also the most severe (Baron-Cohen 1995), of all developmental disorders of childhood. It occurs in every country in which it has been looked for, and across social classes (Baron-Cohen 1995).

## 2.9. HISTORICAL ISSUES

The history of autism stretches back to 1943 when the Austrian psychiatrist Dr. Leo Kanner (1943) first used the term "autism", also known as 'early infantile autism'. At the same time, in Germany, scientist Dr. Hans Asperger described a different, but related, behaviour pattern called "autistic psychopathy" now known as "Asperger"s syndrome". These childhood disorders of social interaction were referred to as autism. The identified criteria for infantile autism included two behavioural features as necessary and sufficient: first, aloofness and indifference to others and, second, intense resistance to change in the child"s own repetitive routines, which had to be elaborate in form. These were onset before 24 months at the latest (Kanner and Eisenberg 1956). Since then, our understanding of autism has changed profoundly. Those impairments became the foundation of the autistic spectrum disorders. The concept of a spectrum of autistic disorders has been developed over the years, which is considered wider than Kanner"s description (Wing & Potter 2002).

In the 1970s, Wing and Gould (1979) developed the concept of the spectrum of autistic disorders, the essential features of which were a triad of impairments of social interaction, abnormalities of language development involving both speech and gesture, and a behavioural repertoire consisting mainly of repetitive, stereotyped activities beginning from birth or within the first few years of life (Wing and Gould 1979).

The DSM-III (APA1980) introduced the term "Pervasive developmental disorders" (PDD) as a general category, thus acknowledging the shift in the concept of autism from a psychiatric to a developmental disorder. There were two subgroups of diagnostic criteria given, namely "infantile autism" with onset before 30 months, and "childhood onset pervasive developmental disorder" with an onset after 30 months but before 12 years (Wing & Potter 2002). Today, autism is recognised as one of a number of related pervasive developmental disorders", which also includes "Asperger disorder".

## 2.10. DEFINITION AND CLASSIFICATION

Internationally, the most widely used definition of autism is based on the DSM-IV-TR (APA 2000) and ICD-10 (WHO 1993). According to these two international classification systems autism spectrum disorders are characterised by qualitative impairment in social interactions, impairment in verbal and nonverbal communication, and by the presence of repetitive / stereotypical behaviour, interest and activities. To receive this diagnosis, the onset of the difficulties in social interaction, communication, and flexible behaviour must be before the age of three years, and can often be reliably detected by this age and in some cases as early as 18 months (DSM-IV-TR 2000; ICD-10 1992).

The term autism is synonymous with the term "Autistic Spectrum Disorder" (ASD) (Wing 1996). The "triad of impairments" has been employed by the ICD-10 as well as DSM-IV-TR to describe the core characteristics for the diagnosis of autism (FPLD 2001). In the DSM-IV, the term "Pervasive Developmental Disability" was used for the general category of autism and related conditions.

## 2.11. DIAGNOSTIC CRITERIA FOR CHILDHOOD AUTISM

The diagnostic criteria for autism have been remarkably consistent and stable over the past several decades since its identification by Leo Kanner in the 1940's (Kanner 1943). Rutter (1996; PP.175) suggests that *"there is a high degree of consensus on the diagnostic criteria for autism and consistency in the evidence on the validation of autism as a diagnostic category"*.

**Kanner's Criteria:** Kanner and Eisenberg (1956) discussed Kanner's original conception of autism and the five features he considered to be diagnostic. There were, a profound lack of affective contact with other people; and anxiously obsessive compulsive desire for the presentation of

sameness in the child's routines and environment; a fascination for objects, which handed with skill in fine motor movements; good cognitive potential shown in feats of memory or skills on performance tests, especially the sequin form board. Kanner also emphasised onset from birth or before 30 months.

In the same paper, Kanner and Eisenberg modified the diagnostic criteria by selecting two as essential. These were:

- (1) A profound lack of affective contact
- (2) Repetitive, ritualistic behaviour, which must be of an elaborate kind.

They considered that, if these two features were present, the rest of the typical clinical picture would also be found (Cited in wing & Potter 2002).

The DSM-IV-TR refers to ASD as "Autistic Disorder". However, the ICD-10 refers to it as "Childhood Autism". For a diagnosis of autism, the Diagnostic and Statistical Manual of Mental Disorders (4th edition; text-revision) (DSMIV-TR; American Psychiatric Association, 2001) requires six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3). Details of the Diagnostic Criteria for autism DSM-IV and ICD-10 are listed in Appendix (IV).

There are different sub-types of autism spectrum disorders (or Pervasive Developmental Disorders (PDD)). The DSM-IV-TR (APA 2000; PP. 70) has identified subgroups of the "autistic disorder", which is closely similar to the ICD -10 (WHO 1993). According to the latest edition of DSM-IV-TR and ICD-10, there are five different disorders included under the broad category of ASD:

- Autistic disorder (DSM-IV-TR) or Childhood autism (ICD-10) (more commonly called autism)
- Asperger's Disorder
- Rett's disorder

- Childhood disintegrative disorder, and
- Pervasive developmental disorder not otherwise specified (PDD-NOS).

The MRC (2001) calls for further research to develop reliable methods to assist researchers in mapping identified impairments onto the currently recognised diagnostic categories.

## **2.12. NATURE OF AUTISM**

The features of the autism disorder vary a great deal from one child to another. Therefore each child with autism is unique, and like all individuals, has an individual personality and combination of characteristics. The autistic characteristics are more likely to change according to the autism disorder level (mild / moderate / severe). For example, children who are mildly affected may exhibit only slight delays in language and greater challenges with social interactions. The child's abilities also may vary, as well as areas of strength and weakness (FPLD 2001).

Children diagnosed with an ASD generally show impairment in three main areas of functioning: social interaction; communication and imagination (repetitive and stereotyped patterns of behaviour, interests, and activities). These include:

### **I. Social interactions**

Children with ASD are characterised by impairments in social interaction, and they have certain difficulties in interpersonal relationship. These difficulties reveal themselves in impaired eye contact, problems with joint attention, paucity in the use of gestures to modulate interactions, and difficulties interpreting others gestures. As a consequence they can behave

inappropriately in social situations (Travis and Sigman 1998; Holt et al. 2004; O'Brien and Pearson 2004; Gabriels and Hill 2002). The lack of social relationships, expressed in attachments and friendships, varies in degrees and nature. Difficulty with social cues affects reciprocal social interaction, joint interactive play and joint attention behaviour and there is a lack of concern for the interests / activities of others or, for that matter, in sharing pleasure or achievement (Read 1997).

## **II. Verbal and nonverbal communication**

Children with autism have difficulty in understanding other people. Pointing is one of the key areas of deficits. The majority of children with autism do not develop functional speech. In particular, children with IQ < 50 do not speak. Children with autism are non-responsive to verbal cues; act as if deaf, although hearing test results are in the normal range. Moreover, there is little or no eye contact, facial expression, body language and use of gestures are very limited. Also, echolalia (repetition of words or phrases heard) is very common. Their communication is more likely described as talking at others instead of to them (O'Brien & Pearson 2004; Gillberg and Billstedt 2000; Holt et al. 2004).

## **III. Social imagination**

It has been suggested that stereotypes and other abnormalities are more common in cases with lower IQ (Eaves and Eaves 1994; Waterhouse et al. 1996) and also it links to the repetitive and ritualistic play of children with autism and associated impairments in social interaction and language (O'Brien and Pearson 2004; Brereton and Tong 2002).

Repetitive stereotyped movements are often the most outstanding manifestation of autism. Children with autism are more likely to spend a lot of time repeatedly flapping their arms or walking on their toes, and may suddenly freeze in position. Repetitive behaviour sometimes takes the form of a persistent, intense preoccupation (Read 1997; Gabriels and Hill 2002; O'Brien and Pearson 2004; Strock 2004).

Another feature of autism is a lack of imagination and creativity. Children with autism often have difficulties to understand and interpret other people's behaviour, thoughts, actions, and feelings. It is also difficult for them to imagine situations outside their immediate daily routine (NAS 2007; Brereton and Tong 2002).

Some children develop an obsessional interest in a topic, hobby or toy. Children with autism may exhibit a fascination with particular objects, and they may have a temper if these objects are lost or removed (Gabriels and Hill 2002).

### **Associated features**

#### *Insistence on sameness; resistance to change*

Routines and rituals become important to many individuals with autism, and they often cling rigidly to sameness in their daily routines (Gabriels and Hill 2002). Additionally, there is often a resistance to change in routine or the environment. The autistic child may become extremely distressed if, for example, a new route is taken to the day centre, or the furniture in the house is rearranged. Children with autism rarely involve others in their activities unless they are given a particular role in a controlled situation (Holt et al. 2004).

#### *Motor impairment*

Children with autism have difficulty with motor skill development (Boucher 1998; Read 1997). This motor impairment includes hypotonia, motor apraxia, reduced ankle mobility, toe-walking, and hand-flapping while bouncing up and down (Minga, Brimacombe, and Wagner 2007; Read 1997).

## 2.13. PREVALENCE

Current prevalence estimates are that between 22/10,000 (Fombonne & Chakribarti 2005) to 25/10,000 children (Baird et al. 2006) have autism. A recent national statistics survey in the UK (2004) suggests that the prevalence of autism spectrum disorders is as high as 1 in 100 people; there are around 500,000 people in the UK with autism (Green et al. 2005; NAS 2007). In the USA, it is estimated 1 per 152 children with autism (Rice 2007). In 2001, it is estimated approximately 1 to 1.5 million Americans with autism based on the autism prevalence 2 to 6 per 1,000 (Centre for Disease Control 2001). Another study of the USA estimated 3.4 of every 1,000 children 3-10 years have autism (Strock 2004). Prevalence studies have reported that autism occurs in all racial, ethnic, and socioeconomic groups. The majority of children with autism are boys (80%), with a male/ female ratio of 4:1 (Green et al. 2005; Fombonne 1999; Fombonne 2003, 2005).

There is growing evidence that the prevalence estimates of children diagnosed with ASD are more common than was previously recognised. There is no consensus as to whether this increase is due to improved diagnostic tools, broadening criteria for diagnosis, or actual increased incidence (Baird et al. 2006). Autism was first identified over 60 years ago (Kanner 1943). When Leo Kanner (1943) first described his classic autistic syndrome, he made no estimate of the possible numbers of people with this condition but he thought that it was rare (Kanner 1943).

20 years after Kanner discoveries, Victor Lotter published the first results of an epidemiological study of children with autism reporting prevalence rates of 4.5 per 10,000 children (Lotter 1966). The decade after, higher rates were reported for broader autism spectrum, with approximately 20 in 10,000 being suggested by Wing and Gould (1979).

Later, in the 1990s, the prevalence rates for autistic disorder were estimated at between 5 -10 per 10,000 in the overall population (Happe 1994; Baron-

Cohen et al. 1996; Gilberg 1999; Fombonne 1999). Baron-Cohen et al. (1996) has proposed that broadly defined autism spectrum disorders might be as prevalent as 6 in 10,000 (0.06%) in 18 month-old children. Whilst in the same year Wing (1996) suggested a rate of around 100 in 10,000 (1%) children. It is possible that the Baron-Cohen study included children with autism at a younger age (18 month-old), and may not include more children with autism with higher ability (Asperger Syndrome), as this form of disorder is not usually identifiable in young children (Howlin and Moore 1997; Scott et al. 2002), this resulted in lower prevalence rates in the prevalence of autism compared to Wing (1996).

Earlier this decade (2000s), autism prevalence rates increased to 60 per 10,000 for all children under the age of 8 years (MRC 2001; Scott et al. 2002; Hare et al. 2003). These studies reported a rise in autism in pre-school children, based on age of diagnosis, and increases in age-specific prevalence rates in children, while the prevalence of autism among adult populations is not known (Wing and Potter 2002; MRC 2001). There are two studies in the UK which used similar criteria for sample of children aged under 7 years, reflecting better ascertainment. These studies are Baird et al. (2000) and Chakrabarti and Fombonne (2001). Baird et al. (2000) estimates prevalence of 57.9 per 10,000 in children (aged 4-6) which occurs with 62.6 per 10,000 for all pervasive developmental disorders reported by Chakrabarti and Fombonne (2001 and 2005). Similarly, Scott and Baron-Cohen et al. (2002) found that the prevalence of autism is 57 in 10,000 for the broader autistic spectrum, including Asperger's syndrome, in 5 to 11 year-olds. Bertrand et al. (2001) also report an ASD prevalence of 67 in 10,000 children aged 3 to 10 years. It can be seen that the prevalence figures from all the ASDs across the four studies are similar. It appears that estimated prevalence rates in the UK has consistently reached as high as 60 per 10,000 for autistic disorder from all studies published by 2002 (Baird et al. 2000; Chakrabarti and Fombonne 2001 & 2005; Scott et al. 2002; MRC 2001; Wing and Potter 2002; Bertrand et al. 2001).

More recently, the survey commissioned by the Office of National Statistics in Great Britain in 2004 indicates that the prevalence is considerably higher (Green et al. 2005), reporting prevalence rates for autism spectrum disorders of 100 per 10,000 (1%) of children between 5 to 16 years. This result concurs with Baird et al. (2006) in a survey for ASD of children aged 9-10 years in the South Thames region, which found an overall figure of 116 in 10,000 for all autism spectrum disorders. Most recently, Baron-Cohen et al. (2009) reported the estimates generated from the SEN (special education needs) register and diagnosis survey of children with autism spectrum conditions aged 5 - 9 year were 94 per 10,000 and 99 per 10,000 respectively. These prevalence rates of autism support previous studies which reported prevalence rates of 100 per 10,000 (Baird et al. 2006; Fombonne 2005; Rutter 2005). Baron-Cohen et al. (2009) indicate also that estimated prevalence, including previously undiagnosed cases, to be 157 per 10 000. Summaries of prevalence studies can be found in table 2.1.

Given this, it could be concluded that the suggested prevalence rates of 1 in 100 (1%) in children is the highest prevalence of autism to date. Thus, it can be inferred that in the last few years, the prevalence of autism nearly increased by 0.4%, from 0.6% to 1%. This increase is most likely due to include a wide children's age range (5 -16 years), as this period includes children identified with other autism spectrums, childhood autism, and also Asperger's, which are often identified in later childhood (Howlin and Moore 1997).

**Table 2.1. Prevalence studies of autism spectrum disorder**

Authors	Year	Sample & age (per year)	Rate per 10 000	Diagnostic criteria
Lotter	1966	Autism	4.5	Kanner's
Wing and Gould	1979	Broader ASD and LD	20	Kanner's
Gillberg et al.	1986	Autism	20	DSM-III
Gillberg et al.	1991	Autism! ASD	8.4 ! 3.2	DSM-III R
Ehlers & Gillberg	1993	Autism & Asperger	36	Gillberg
Baron-Cohen et al.	1996	Broader ASD, 1.5	6	
Honda et a l.	1996	Autism	21.1	ICD-10
Californian Dep.	1997	For birth year.	31.2	DSM-IV
Gillberg & Wing	1999	Autistic ! childhood autism	10	DSM-III R! ICD-10
Kielinen et al.	2000	Broader ASD	20.7	DSM-IV
Baird et al.	2000	Broader ASD 4-6	57.9	ICD-10
Fombonne et al.	2001	ASD	26	DSM-IV
Bertrand et al.	2001	ASD 3-10	67	DSM-IV
Chakrabarti & Fombonne	2001	PDD! Autism 2.5 -6.5	62.6 ! 16.8	DSM-IV
Scott et al.	2002	Boarder AS 5-11	57	DSM-IV ! ICD-10
Hare et al.	2003	> 8	60	N!A
Strock	2004	Autism, 3-10	3.4	DSM-IV
Chakrabarti & Fombonne	2005	ASD	45	DSM-IV
Green et al.	2005	Autism	100	ICD-10
Fombonne et al.	2006	PDD! autism	64.9 !21 .6	DSM-IV
Baird et al.	2006	ASD ! autism 9-10	116! 25	ICD-10
Baron-Cohen et al.	2009	diagnosed cases of Autism ! autism spectrum conditions 5-9	99 ! 157	ICD-10

This increase has not only been reported in the UK, but worldwide. This is illustrated by the fact that in California the estimated prevalence rate is around 31.2 per 10,000 for the birth year 1997 (The California Department of Developmental services 2002). Another study reported a steady rise in the annual incidence of autistic disorders (Dales et al. 2001). It is reported that in the state of California (2003) in the four years from 1998 to 2002 the number of autism cases nearly doubled (increased by 97%).

Furthermore, in Canada, a cohort birth study by Fombonne et al. (2006) estimated the prevalence of pervasive developmental disorder from 1987 to 1998 of around 65 per 10,000. Fombonne et al. (2006) state that there is significant linear increase in pervasive developmental disorders, as reported in the period of the study.

In Europe, a Danish population cohort based study by Atladóttir et al. (2007) examined trends of autism from 1990 to 1999, state that significant increases were found in cumulative incidence across specific birth years for autism spectrum disorder, childhood autism, hyperkinetic disorder, and Tourette"s syndrome.

Evidence over the last few years indicates that autism is identified more than ever before. A comprehensive review study for 39 studies on the prevalence of autism published in the English language was conducted by Wing and Potter (2002) who reported that there is a marked tendency over time for an increase in the rates to be found.

It is important to identify what contributes to the apparent rise in autism. The early studies yielded prevalence rates of about 60 in 10000 children, whereas the later ones showed a mean rate of about 100 in 10000. There is a marked increase in the prevalence rates recently. It can be argued that the increasing prevalence of autism is attributed to a number of factors. These include: the adoption of a much broader conceptualisation of autism

spectrum as a disorder rather than a core categorical condition. Thus, a widening of the diagnostic criteria, owing to changes in diagnostic criteria, the earlier identification and, therefore, better identification of children, and then the results of research and clinical work have led to the broadening of the concept of autistic disorders (Baron-Cohen et al. 2009; Fombonne et al. 2006; Wing and Potter 2002; MRC 2001; Charman 2003). Moreover, this increase is arguably due to the greater awareness and recognition of autism among professionals, parents and the general public, resulting in higher prevalence figures (Baron-Cohen et al. 2009; Fombonne et al. 2006; Baird et al. 2003; Mayor 2003; Wing and Potter 2002; MRC 2001; Ghaziuddin 2000; Brereton & Tong 2002; Baron-Cohen, Allen and Gillberg 1992). Differences in methods used in the studies, such as size of target population and methods of identifying cases, also play a role in detecting the prevalence of autism (MRC 2001; Wing and Potter 2002), and therefore better identification of children with autism in communities and epidemiologic surveys, improved access to services and the increase in available diagnostic services (Baron-Cohen et al. 2009). For example, the development of specialist services for autism spectrum disorders and improved access to these services (Wing 2002; Wing and Potter 2002) has also contributed to a better diagnosis, and resulted in increased awareness of the spectrum. And finally, there is also increased recognition of the co-morbidity with ASD and LD (Wing and Potter 2002), as well as increasing detection of autism among typically developing children (Fombonne et al. 2006).

Although Wing and Potter (2002) suggest that it is possible to attribute the increase of the prevalence of autism to true increase in numbers, it is argued that the phenotype of autism has not increased over time (Fombonne et al. 2006). If autism increased over time then the aetiology of autism disorders should be related to the environmental risk factors rather than the gene interactions, yet in fact environmental risk factors have very little influence.

“If changes in the incidence of PDDs were demonstrated, they might point toward environmental risk factors contributing to the aetiology of the disorder, with or without gene interactions. Few environmental exposures that occur during the prenatal period have been related to increased risk of PDDs, and such factors account for only a tiny fraction of the population risk”.

(Fombonne et al. 2006; PP. e140)

Although there is some degree of the true rise in the prevalence of autism over time (Rutter 2005), it is argued that it is a false increase in prevalence estimates (Charman 2003). As noted above, the explanation of this massive increase is likely due to various factors including improved recognition and the broadening of the diagnostic concept, changes in study methodology, an increase in available diagnostic services, increased awareness among professionals and parents, growing acceptance that autism can coexist with a range of other conditions; and a widening of the diagnostic criteria (Rutter 2005; Baron-Cohen et al. 2009).

It can be concluded that estimates of the prevalence of autism and related ASDs have increased considerably. Although it is not easy to compare studies across time as a result of change in diagnosis and different methodology, this increase is a genuine prevalence of autism (MRC 2001). Whether the reason for this increase is due to any of those mentioned above, the needs of children with ASD, who constitute 1% of the children population should be recognised by health services, education, and social care.

Further research is needed to identify reliable prevalence to identify whether there has been a true rise in the numbers of children with the autistic disorders and, if so, how large it is and whether it is still continuing to rise (Wing and Potter 2002). Also, future work is needed to develop reliable methods of the epidemiology of autism spectrum conditions in order to identify the attributes factors of this rise (Scott et al. 2002). The following section discusses the aetiology of autism in detail, in terms of the genetic contribution and also will refer to the recent review regarding its association with the MMR.

## 2.14. AETIOLOGY

Autism is caused by abnormalities in brain structure or function, however there is not yet consensus of a single known cause for autism. Most experts would comment that autism is due to a variety of aetiologies affecting the developing brain. The genetic component has been established. However, the specific genetic basis for autism is not clear.

- Genetic cause

Research evidence indicates that complex genetic influences are contributing to pathogenesis in approximately 90% of autism according to the DSM-IV (MRC 2001; Wing and Potter 2002), although the mechanism is not yet understood. Neither is it known how genetic susceptibility interacts with environmental factors (Baird et al. 2003; Berney 2000). Genetic studies have indicated that RELN gene is associated with autism (Skaar et al. 2005; Hutcheson et al. 2003; Philippe et al. 1999). Evidence according to Skaar et al. (2005) “*strongly suggests that RELN is involved in autism susceptibility, although further work is necessary to identify the specific variations with direct effects*” (PP. 569). It is suggested that many of the pathogenic mechanisms proposed as causing secondary autism appears to be environmental stressors bringing out a genetic vulnerability (Berney 2000). Family study has identified six potential chromosomes 7q and 1 6p (International Molecular Genetic study of autism consortium 1998). Recently, a genetic study identified that 16p.112 microdeletions are a risk factor for autism spectrum disorders generally, and may cause mild autism in some families (Arking et al. 2008).

The genetic aetiology is strongly suggested due to several reasons. Firstly, brain scans show differences in the shape and structure of autistic children to non - autistic children. Twin and family studies have demonstrated autism is highly heritable, and there is a pattern of autism or related disabilities in many families. Many genes probably interact to make a child vulnerable to

autism. There is progress being made by international collaborative groups to identify these genes (Arking et al. 2008; International Molecular Genetic study of autism consortium 1998; Holt et al. 2004; MRC 2001).

- Other factors

Many other causes have been proposed, such as environmental toxins (e.g. heavy metals such as mercury). Those individuals with ASD (or those who are at risk) may be especially vulnerable, as their ability to metabolise and detoxify these exposures can be compromised. In addition, dietary exclusion of gluten and casein has been suggested to affect autism (Berney 2000; MRC 2001). There are some case studies that reported clinical improvement in children with autism placed on gluten and/or casein free diets (Whitely et al. 1999; McCarthy and Coleman 1979). Although there have been a number of positive reports about its effectiveness, the evidence needs further investigation (Berney 2000). Moreover, the MRC (2001) indicated that there are no properly controlled studies describing the effects of gluten and casein free diets in autism. It is also indicated that mercury can have serious effects on the developing brain, although there is no conclusive evidence for elevated levels of mercury in children with autism (MRC 2001).

- MMR

It has been hypothesised that there is a causal link between the MMR vaccine and ASD (Wakefield 1998). However, the current epidemiological evidence does not support the proposed link of MMR to ASD (MRC 2001; Demicheli 2005). The most recent research study (Hornig et al. 2008) indicates that no evidence was found to relate the MMR vaccine to autism. Recently, the Department of Health (2008) has reviewed the new study by Hornig et al. (2008) that replicates the methods of the original study even using, along with another two laboratories, the same laboratory that Wakefield and his colleagues (1998) used to analyze their samples. The researchers (Hornig et al. 2008) conclude that their study provides strong

evidence against any association of autism with persistent measles in the bowel or with the MMR vaccination. Similarly, Baird et al. (2008) emphasizes that there is no association between MMR and ASD. This is a confirmation of what has been concluded by the MRC (2001), that being that there is no evidence to support the proposed link between MMR and autism.

There is an interesting influence of what has been suggested of the relationship between MMR and ASD. Whereas research evidence argues against claims of an association with MMR vaccine and ASD (MRC 2001; Fombonne et al. 2006; Baird et al. 2008; Horing et al. 2008), over the last 10 years since the first published study (Wakefield 1998) there has a powerful influence in drawing people's attention (professionals and parents) to the presence of the ASD condition (Wing and Potter 2002).

All the above factors highlight the complexity to the genetic component of autism. Although there is strong evidence that genetic factors play a dominant role in aetiology, it is unclear which genes are responsible. Environmental factors that interact with genetic susceptibility are not clear yet (MRC 2001; Peeters and Gillberg 1999). Other factors have been proposed, but also remain controversial, and research demonstrated no link associated with MMR and ASD.

## **2.15. LEARNING DISABILITIES, AUTISM AND MENTAL HEALTH PROBLEMS**

## **2.16. CO-MORBIDITY OF LD AND AUTISM**

Kanner (1943) and Lotter (1963) did not identify the relationship between autism and LD. The first attention was brought to bear on the association with LD and ASD when DeMyer et al. (1974) and Wing (1976) reported the fact that there is a differential diagnosis between autism and learning

disabilities, understanding that the two conditions can coexist. Since then, other research has investigated the association between the two disorders. Recently, several studies have drawn attention to the co-morbidity of autism and learning disabilities (e.g. Seidel et al. 2007; La Malfa et al. 2004; Hare et al. 2003; Morgan et al. 2002; Gillberg and Coleman 2000; Ghaziuddin 2000; Nordin and Gillberg 1996).

*Children with co-morbidity LD and autism (learning disabled autistic people)*

“In most cases [of autistic disorders], there is an associated diagnosis of mental retardation [LD], which can range from mild to profound”  
(APA 2000; PP. 71)

It is suggested that LD is probably functioning normally in children with autism (Baron-Cohen 1995). The autism and LD typically coexist together (Wing and Potter 2002). According to the DSM-IV-TR, and ICD-10, children with autism also have a learning disability. There is a significant association between autism and LD (75%), ranging from mild to severe levels, in most cases (APA 2000; WHO 1993).

It is well known that there is a highly significant association between LD and autism. On one hand, epidemiological studies reported that autism is more frequent among people with LD, with prevalence estimates ranging from 14.3% (Deb and Prasad 1994) to 30-40% (La Malfa et al. 2004; Morgan et al. 2002; Bouras 1999; Kraijer 1997; King et al. 1994). Moreover, the higher prevalence level of autism increases in relation to the lower level of IQ (Hare et al. 2003; Department of Health 2001; Smalley et al. 1998; Deb and Prasad 1994; Wing 1993). In addition, some children with LD display autistic features, without fulfilling the criteria necessary for a diagnosis of autism (Gillberg and Coleman 2000). Similarly, recent prevalence studies focused on children and adolescents with LD in the USA where DeBildt et al. (2005) identified prevalence rates of autism of around 16.7% in children with LD according to DSM-IV-TR.

On the other hand, research has consistently shown that LD co-occurs in most cases of autism spectrum disorders, with around 70-75% of children with ASD having mild to moderate LD (La Malfa et al. 2004; Fombonne 2003; Ghaziddin 2000); and 25-48.4% with severe LD (Bouras 1999; Kraijer 1997; Gilberg et al. 1986). However, other studies have reported lower prevalence rates of LD within the whole of autism, and found this percentage might vary from 25% to 55% (Chakrabarti and Fombonne 2001; Baird et al. 2000). Comparing this to the prevalence of autism in the general population shows that this is 1% according to the DSM-IV-TR (Green et al. 2005; NAS 2008). It is more likely that autism is still more frequent in people with LD (Baird et al. 2000). Baron-Cohen (1995) explains why the majority of children with autism also have learning disabilities. Most children with autism do not reach the milestones associated with normally developing children, therefore cognitive, social, and motor development corresponds to mental age rather than to chronological age.

This variation in prevalence rates of LD and autism identified seems to be as a consequence of associated factors. These include the concepts of autism under study, the sampling methods used in the study and the instruments used, and the study participants characteristics (e.g. level of LD, age, gender, medical or genetic conditions, and family history) as well as the instrument used (De Bildt et al. 2005; Bradley 2004).

Although most research suggests an association of LD with autism, a recent systematic review has challenged this co-morbidity. Edelson (2006) argues that the idea that the majority of children with ASD have LD is not warranted. This argument built on the systematic evaluation of 215 articles claiming this co-morbidity, from 1937 to 2003. According to Edelson most of the claims originate from non-empirical sources that don't use empirical data, cite empirical research that is 25-45 years old, and used inappropriate measures, or typically failed to acknowledge the possible interference of autism on the assessment of intelligence (Edelson 2006; PP. 74). Freeman and Van Dyke (2006) supported the above review, and emphasise that when children have

autism, despite the cognitive deficits, this does not mean the majority of children with autism have learning disabilities.

Overall, the evidence indicates that there is a significant association between autism and LD and the two conditions are co associated. Meanwhile, the research of awareness of the coexistence of ASD and LD is still growing (Croen et al. 2002) and, therefore, more empirical research is needed to identify the prevalence rate of this co-morbidity between autism and LD (Edelson 2006).

## **2.17. PREVALENCE OF MENTAL HEALTH PROBLEMS IN CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES AND AUTISM**

One of the most consistent findings to emerge in recent years is the increased prevalence of mental health problems and behaviour disorders among individuals with LD compared with the general population (Emerson 2003; Bradley 2004; Emerson and Hatton 2007). Moreover, young people with autism have shown more prevalence for mental health problems than other young people with LD without autism (Brereton et al. 2006; Hill and Furniss 2006; Bradley et al. 2004). All types of mental health problems are seen in young people with LD as in the general population. Children and young people with autism and with mild to moderate LD are more prone to experience mental health problems than the general population, and although they have greater levels of mental health needs than general population, these are often unrecognised (Hatton 2002; Royal College of Psychiatry 2004; Raghavan 2004; Cooper et al. 2004; Smiley 2005).

In prevalence studies, the terms mental health and mental illness are used interchangeably to refer to psychological disorders in the normal function of a person (Raghavan and Patel 2005; Smiley et al. 2005). Also, terms such as mental illness, mental disorders, psychiatric illness, psychiatric disorder,

emotional problems and behavioural disorders have been used to refer to mental health problems. Hence, this difference in types of disorder can have a considerable effect on reported prevalence rates and makes the comparison of studies complicated (Smiley 2005). The term “mental health problems” will be used throughout this thesis.

### **2.17.1. Learning disabilities and mental health problems**

There is no simple way to estimate how many young people there are with LD and who also have mental health problems. Epidemiological studies broadly demonstrate that the prevalence of both mental health problems and challenging behaviour are higher among people with LD compared with other young people (Emerson and Hatton 2007; Allington-Smith 2006; Raghavan and Patel 2005; Smiley 2005; Lidher et al. 2005; Bradley 2004; Emerson 2003; Deb et al. 2001; Moss et al. 1998; Pyles et al. 1997; Borthwick-Duff 1994). People with LD show higher prevalence of challenging behaviour, with a rate of around 10-14% (Borthwick-Duff 1994; Emerson et al. 2001; Holden and Gitlesen 2003) and estimated rates of 20.5% for conduct disorders (Emerson and Hatton 2007).

The Office of National Statistics (ONS) carried out the first major UK-wide epidemiological study of the Mental Health of Children and Adolescents in Great Britain in 1999 (Meltzer et al. 2000). The survey identified that the prevalence of known children and adolescents with LD (aged 5-25 year olds) mental health problems is around 10%. Secondary analysis of the 1999 Office for National Statistics survey performed by Emerson (2003) has shown that mental health problems are over-presented in children and young people with LD (5 - 15 years) compared to the general population.

People with LD are at significant increased risk of certain forms of psychiatric disorder. These include conduct disorder, anxiety disorders, hyperkinesia and pervasive developmental disorders. This analysis is comparable to the recent secondary analysis for both the 1999 and 2004 National Statistics

surveys reported by Emerson and Hatton (2007). Research evidence indicates that there is stability in the prevalence of mental health problems and challenging behaviour over this period in children and young people with LD (Emerson and Hatton 2007; Chadwick et al. 2005). The following is a case in point: Emerson and Hatton (2007) illustrate that the prevalence of mental health problems in children and young people with LD is 36% compared to 8% for non-disabled peers. This is nearly consistent with earlier estimated prevalence in 2002 suggesting that approximately 40% of children with LD experience mental health problem, whereas this is just 10% among young people without LD (FPLD 2002). It can be inferred that young people with LD have consistently been found four times more likely to have mental health problems than other young people (Emerson and Hatton 2007; Kaptein et al. 2007; Cooper et al. 2005; Simonoff 2005; Wilson 2004). Meanwhile, the facts and figures of LD in the UK report that young people experience mental health problems 6 times more than their non-disabled peers (Learning disabilities: facts and figures, Department of Health: accessed online 2007).

In general, the reported prevalence of mental health problems in people with LD varies widely between 20-50% (Raghavan 2004; Copper and Bailey 2001; Dekker and Koot 2003; Count Us: FPLD 2005; Morgan et al. 2008). Prevalence studies concern children and young people with LD have identified higher prevalence rates for Mental health problems, at for example: 38% (Emerson 2003; Emerson and Hatton 2007), 40% (FPLD 2002) and 50% (Cormack et al. 2000), and 61% (Kaptein et al. 2007).

The reasons for this variation in prevalence rates are due to the differentiation in the definition of mental health problems and the use of different instruments and assessment approaches (e.g. semi-structured clinical interviews, file reviews, observations, and rating scales) to assess these problems. Additional factors include the characteristics of the individuals being evaluated (e.g. their level of LD, age, gender, medical or genetic conditions, family history), and the sampling methods used in the

study (Kaptein et al. 2007; Dekker et al. 2002; Dekker and Koot 2003; Raghavan 2004; Smiley 2005; Borthwick Duffy 1994). Another factor includes reporting the combined prevalence for children and adults; thus reporting mental health problems in total (Cooper et al. 2007). As a result it is not possible to find accurate prevalence rates of mental health problems.

### **2.17.2. Autism and mental health problems**

However, there has only been a limited amount of research concerning mental health problems in children and young people with autism (Hartley et al. 2008; Simmonoff et al. 2008; Herring et al. 2006; Brereton et al. 2006; Kim et al. 2000; Tsai 1996; Ghaziuddin, Alessi & Greden 1995). It has been shown that mental health problems occur at particularly higher rates in children and young people with autism compared with other children without autism or LD (Gillberg and Billstedt 2000; Gadow et al. 2004; Herring et al. 2006). Brereton et al. (2006) comparing the psychopathology in young people with autism to young people with LD, has shown that young people with autism present more mental health problems, such as anxiety, depression, attention deficits hyperactivity, self-absorbed and more problems with communication and social relating, compared to young people with LD without autism. In a more recent study, Hartly and McCoy (2008) report 33% prevalence rates of mental health problems in young children with autism. This concurs with Green et al. (2005) reporting 30% of children with autism have another mental health problem.

Given this, mental health problems are greater in children and young people with LD, as well as in children and young people with autism, compared to the general population. It can be deduced that mental health problems in children and young people with co-morbid LD and autism are expected to be higher.

### **2.17.3. Co-morbid learning disabilities and autism and mental health problems**

Recent evidence has indicated that young people with co-morbid autism and LD are more prone to experience mental health problems compared to people without autism. To date, there are only two comparative studies which report the prevalence of mental health problems in adolescents and adults with co-morbid severe LD and autism.

The first study conducted on the issues in Canada was by Bradley et al. (2004). This study compared prevalence rates of psychiatric and behaviour disorders in two groups, one group of adolescents and young people diagnosed with autism and severe LD, and the other without autism. People with LD and autism reported significantly greater disturbances of mental health problems as measured by DASH-II total score (seven of 13 disturbances). This group also found 5.25 clinically significant disturbances compared with 1.25 disturbances for group without autism. Bradley et al. (2004) indicate that this group with LD and autism have specific vulnerabilities to anxiety, mood, sleep, organic syndromes, and stereotypes / tics. Those were the most common problems in this group.

The second prevalence study was conducted in the UK by Hill and Furniss (2006), and this study examined the prevalence of emotional and behavioural disturbance in adults with severe LD without autistic features comparing it with other two groups with LD with varying severities of autism (severe and moderate), assessed by DASH-II. Results indicate that individuals with autism were found to have significantly higher scores than individuals with LD but without autism on the DASH-II. The findings are consistent with the above study of Bradley et al. (2004) indicating that people with severe LD and autism (severe and moderate) show higher scores for anxiety, mood, stereotypes, mania and PDD/autism on DASH-II subscale scores than people with comparable levels of LD without autism.

The indications are therefore that co-morbidity of LD and autism suggests high rates of mental health problems. Young people with LD, autism and mental health often face more difficulties negotiating the tasks of adolescence than their non-disabled peers. LD and mental health problems seem to have increased considerably among young people in the past 20-30 years. One explanation for this is that the rise has been driven by social change, including disruption of family structure, growing youth unemployment, and increasing educational and vocational pressures (Michaud and Fombonne 2005).

There are many factors associated with the increased prevalence of mental health among children and young people with LD and autism, for instance, language delays, communication difficulties and / or sensory impairments (Cooper et al. 2005). This might occur if the child feels that his needs are thwarted (O'Brien & Pearson 2004). Moreover, children with autism's characteristics have a great risk to develop mental health problems. The child's gender has an influence on the prevalence of mental health problems, for example males rather than females are more likely to have a diagnostic disorder and conduct disorder (Emerson 2003). Social exclusion and lack of social and cognitive resources to cope with adulthood are also thought to contribute to this vulnerability to social and emotional problems (Wilson 2004). In addition, children with LD are more likely to experience stressful life events (Emerson 2003).

Furthermore, mental health problems are more common in certain family circumstances, such as lone parent families compared with two-parent families (Emerson 2003; Green et al. 2005), living in low income and high unemployment areas, unhealthy patterns of family functioning and child management practices and carers' mental disorders (Green et al. 2005). Prevalence studies reported that children of lone parents, also living in lower income households, are more likely to have emotional disorders e.g. anxiety and depression (Green et al. 2005; Raghavan and Patel 2005; Emerson 2003; Meltzer et al. 2001).

### ***The most common mental health problems with learning disabilities and autism spectrum disorder***

A wide range of mental health problems have been reported among children and young people with LD. These mental health problems may cover a range of problems from relatively mild emotional disorders, such as anxiety and mild depression (FPLD 2002; Howlin 1998) to serious psychiatric disorders. Challenging behaviours and behaviour disorders may also present and co-exist in people with LD, including physical aggression, destructiveness, self-injury, stereotypes and inappropriate social behaviours (such as difficult sexual behaviour) (FPLD 2002; Allen and Davies 2007).

Similarly, a growing number of mental health problems have been reported in children with autism compared to other children (Gillberg and Billstedt 2000; Gadow, DeVincent, Pomeroy and Azizian 2004). It has been suggested that depression and anxiety are the most prevalent relative mental health problems associated with autism (Hill and Furniss 2006; MRC 2001; Howlin 1998). Meanwhile, other mental health problems have been reported, for instance: withdrawal, attention, and aggression (Hartley & McCoy 2008), social anxiety (Bellini 2004; Gillott; Furniss and Walter 2001), high anxiety or fears (Fombonne 1997; Kim et al. 2000; Gillott, Furniss and Walter 2001), obsessive compulsive disorders (McDougle et al. 1995), and mood disorders (Lainhart and Folstein 1994; Ghaziuddin, Ghaziuddin & Greden 2002; Bradley, Summers, Wood and Bryson 2004).

Prevalence studies indicate that anxiety ranks among the most prevalent mental health problems in children and young people with LD and autism (Hill and Furniss 2006; Emerson and Hatton 2007; MRC 2001, Kim et al. 2000; Howlin 2000; Tantam 2000). Researchers and clinicians have subsequently considered anxiety as both a possible consequence of, and a possible cause of, aspects of behaviour of children with autism (Gillott et al. 2001). Thus, this research focuses on anxiety in young people with LD and autism, and this will be discussed in greater detail in the next section.

## 2.18. ANXIETY IN CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES AND AUTISM

This section describes anxiety in children and young people with LD and autism, the prevalence of anxiety, and highlights risk factors for increased prevalence as well as theories of autism and anxiety.

## 2.19. DIAGNOSIS AND CLASSIFICATIONS OF ANXIETY

Anxiety can be classified according to its clinical features. The following disorders are included in anxiety: Generalized Anxiety disorder, Panic Disorders, Specific Phobia, Social Phobia, Acute and Posttraumatic Stress (PTSD), Obsessive-compulsive disorder (OCD), Panic attack, Agoraphobia, Separation anxiety and Anxiety not otherwise specified (DSM-IV-TR: APA 2000; WHO 1993).

### Description of DSM-IV anxiety disorders (APA 2000; PP. 429)

#### **Anxiety disorders**

- **Panic Disorder:** Characterized by recurrent and unexpected panic attacks. It can occur with or without Agoraphobia.
- **Separation Anxiety Disorder:** Developmentally inappropriate and excessive anxiety surrounding separation from home or from significant attachment figures.
- **Specific Phobia:** Characterized by significant anxiety provoked by exposure to a feared object or situation, often leading to avoidance.
- **Social Phobia:** Characterized by a significant anxiety provoked by exposure to a specific type of social or performance situation, often leading to avoidance behaviour.
- **Obsessive compulsive Disorder:** Characterized by obsessions that cause marked distress and/or by compulsions, which are performed to neutralize anxiety.
- **Post-Traumatic Stress Disorder:** Characterized by the re-experiencing of an extremely traumatic event accompanied by increased arousal and avoidance of stimuli related to the trauma.
- **Generalized Anxiety Disorder:** Characterized by at least 6 months of persistent and excessive anxiety and worry.

## **2.20. PREVALENCE OF ANXIETY IN PEOPLE WITH LEARNING DISABILITIES AND AUTISM**

It is suggested that many studies fail to make a definite diagnosis for anxiety in children with LD and report only the prevalence of anxiety symptoms (Bailey & Andrews 2003). Moreover, with more severe LD, only behavioural symptoms can be assessed reliably and this often makes it difficult for all the criteria of an anxiety disorder to be met (Matson et al. 1997).

### **2.20.1. Anxiety and learning disabilities**

Anxiety is highly prevalent in children and young people with LD compared with typically developing peers. Prevalence studies in the UK have consistently reported that the prevalence of anxiety is significantly higher in children and young people with LD compared to the general population according to ICD-10 (Meltzer et al. 2000; Deb et al. 2001; Emerson 2003). A literature review (Raghavan 1998; Cooray and Bakala 2005) indicated that the prevalence of anxiety is similar, if not higher, in people with learning disabilities.

Estimates of the prevalence of anxiety range from 8.7% (Emerson 2003) to 21.9% (Dekker and Koot 2003) in children with LD. Another study indicates higher rates of up to 30% (Reiss 1990). These rates seem to be higher than those reported for children without LD, which is 5.7% (Costello et al. 1996). Similarly, Emerson (2003) reports 3.6% for non-disabled peers. Little research has been undertaken with individuals with severe and profound LD. Matson et al. (1997) illustrate that there is doubt on the accuracy of the anxiety diagnosis in people with severe LD, as it often gets confused with behaviour disorders and this should be assessed with caution. Prevalence studies of autism are shown in table 2.2.

It has been suggested that anxiety varies significantly for the different subtypes of anxiety disorders (Raghavan and Patel 2005). This means some

subtypes are less common in people with LD and others are more common than or as common as those in the general population (Reiss 1993). It is reported that sometimes anxiety can be out of all proportion to the cause or may be specific to something in particular (phobia). Other developmental disorders, especially autism, may also make young people more susceptible to anxiety (FPLD 2002).

**Table 2.2. Prevalence studies of anxiety in people with LD**

Study	Year	Sample age ( years)	Assessment of anxiety	Prevalence
<b>Li et al.</b>	2006	Children and adolescents with mild & moderate LD/ 7-18 yrs.	Fear survey schedule/ Revised children's manifest anxiety scale	Highest level of fears related to failure and criticism
<b>Dekker and Koot</b>	2003	474 children and adolescents/ 7 to 20 yrs.	N/A	21.9% of children met anxiety on DSM-IV-TR
<b>Emerson</b>	2003	264 children 5-15 yrs.	Secondary analysis of 1999 ONS	8.7% rates of anxiety
<b>Deb et al.</b>	2001	Adult (16-64 yrs.) LD comparing with general population	N/A	Higher rates of phobic disorders
<b>Reiss</b>	1990	N/A	N/A	31 % of anxiety
<b>Cooper</b>	1997	Elderly people and younger age with LD	N/A	Higher rates for anxiety in the elderly than younger

N/A: Not Available

### 2.20.2. Anxiety and autism

Individuals with autism are more prone to suffer from anxiety. Young people with autism experience anxiety at a greater level than other young people without autism (Bellini 2004 a; Kim et al. 2000; Holt et al. 2004; Gillott et al. 2001). Children and young people with autism compared to others with LD

were found have high levels of anxiety for the autistic group using the Developmental Behaviour Checklist (DBC-P) (Brereton et al. 2006). It is indicated that they are almost three times more anxious than others (Gillott & Standen 2004; Waller and Furniss 2004). Epidemiological studies estimate the prevalence of anxiety in children and young people with autism ranges from 13.6% to 84% (Kim et al. 2000; Rumsey, Rapoport & Sceery 1985; Tsai 1996; Muris & Steernman 1998; Gillott, Furniss and Walter 2001). Muris & Steernman (1998) reported 84% of children with autism met the full criteria of at least one anxiety disorder. Gillott et al. (2001) reported around 47% of children with high functioning autism had clinically significant levels of anxiety. Most recently, Sukhodoisky et al. (2008) reported that 43% of children with PDD (including autism) met one or more criteria of the DSM-IV-TR anxiety. This variation is more likely due to the use of different methods, and different characterises of the sample. More details of the prevalence studies are shown in table 2.3. With regard to the age of the participants, this varied from one study to another.

For studies concerning children, the age ranged between 3-14 year-olds (i.e. Weisbrot et al. 2005; Kim et al. 2000; Lecavalier 2006; Sukhodolsky et al. 2008). Other studies involved young people ranged from 12 to 20 years old (Bellini 2004 a; Simonoff et al. 2008; Farugia & Hudson 2006; Bradley et al. 2004). However, few studies involved both children and young people aged 2-18 years (Muris & Steernman 1998; Gillott et al. 2001). The sample size varies according to the study, the number of participants included a small sample size (25 - 41 children and young people); to a large sample size (171 - 487 children and young people).

**Table 2.3. Prevalence studies of anxiety in people with autism.**

Study	Year	Sample / age (year)	Assessment of anxiety	Prevalence
Sukhodolsky et al.	2008	171 children with autistic disorders (PDD / 5-14	Parent report	43% met at least one anxiety. Higher anxiety with high IQ
Simonoff et al.	2008	112 young people with ASD / 10-14	Interviewing parent	41% met criteria for at least one anxiety
Lecavalier	2006	487 children with ASD / 3-12	Parent-report	Higher prevalence rate of anxiety
Farrugia & Hudson	2006	29 adolescents with AS. compared to 30 nonclinical and 34 with anxiety, aged 12-16	Self- and parent-report	Anxiety significantly higher for the AS compared to non clinical and anxiety groups
Evans et al.	2005	25 children with ASD	Parent report, fear survey	Children with ASD scored more higher than down syndrome
Weisbrot et al.	2005	Children with PDD, aged 3-12	Early Childhood Inventory-4/ child Symptoms Inventory-4	Children with PDD are rated as having anxiety symptoms more than non-PDD
Bellini	2004a	41 young people with autism, AS,PPD- NOS, aged 12-18	Social skills rating system	49% scored high for social anxiety. Significantly higher than general population
Bradley et al.	2004	12 young people with autism aged 12-20	DASH-II	Higher than group without autism on anxiety subscale
Gillott et al.	2001	15 Children and adolescent With autism	Spence Children's Anxiety Scale Self report & parent report	47%, Higher level of social anxiety than general population
Kim et al.	2000	59 children with AS & HFA, aged 9-14	Parent-report on a Battery of cognitive and behavioural measures	13.6% scored at least 2 standard deviation above the mean for anxiety
Muris & Steernman	1998	44 children and young people with ASD aged 2-18	Parent interviewed using Anxiety section of the Diagnostic Interview Schedule for Children	84% met at least one anxiety

HFA=High functioning autism, AS= Asperger's Syndrome, PPD= pervasive developmental disorders, ASD= autism spectrum disorders.

Currently, the evidence for a link between anxiety and autism, as well as anxiety and LD, are reasonably strong. Anxiety has repeatedly been found to be associated with LD (Raghavan and Patel 2005; Emerson: 2003; Whitaker & Read 2005) and also autism (Kim et al. 2000; and Gillott et al. 2001; Bradley et al. 2004; Bellini 2004; Waller and Furniss 2004). Despite this, less is known about the prevalence of anxiety in children and young people with comorbid LD and autism. This is more likely as a result of the lack of standardised measures for this clinical population, or the difficulties of using informant-rated measures (Gillott et al. 2007).

While little research has been concerned with mental health problems in adults with co-morbid severe LD and autism (Hill and Furniss 2006, Brereton et al. 2006, and Bradley et al. 2004), there has been no research focusing on anxiety in children with mild to moderate learning disabilities, and in particular co-morbid LD and autism. The research evidence available, which examines mental health problems in individuals with co-morbid LD and ASD, suggests that as a group diagnosed with both disorders ASD and LD they demonstrated higher prevalence rates of anxiety compared to people with LD but without autism (Bradley et al. 2004; Hill and Furniss 2006; Brereton et al. 2006). Where there is gap in the literature concerning the prevalence of anxiety in children and young people with LD and autism, further research that might assess and identify the prevalence of anxiety in a group of children and young people with mild and moderate LD and autism is required.

As discussed in the above section concerning mental health problems in people with LD and autism, there is agreement that the prevalence of mental health problems is greater among children and young people with co-morbid LD and autism. The findings of Hill and Furnnis (2006) revealed that adults with autism and severe LD demonstrated higher levels of anxiety than other groups without autism. This finding concurs with Bradley et al. (2004) who,

using the same screening instrument DASH-II, also found that adolescents with autism and severe LD are more vulnerable to anxiety.

Research studies available indicate an association between anxiety and autism (Gillott et al. 2007; Hutton et al. 2008). However, it is not clear yet if these symptoms (of anxiety) are features of autism or a separate disorder (Hutton et al. 2008; Weisbrot et al. 2005). It is important to explore whether autism or IQ can contribute to the greater prevalence of anxiety. In a recent study, Sukhodoisky et al. (2008) suggest that there is a positive association between anxiety and IQ, and that the higher IQ the more severe anxiety. The findings of this study have shown that some anxiety is greater in children with autism and a higher IQ (mild to moderate LD). This is also consistent with other studies (Lecavalier 2006; Weisbrot et al. 2005). According to Ghaziuddin (2000), those children with autism with higher IQ levels are more prone to mental health problems than autistic children with LD, because of their greater insight into their deficits. Furthermore, research on people with autism and LD, investigating the mental health problems in this group, have consistently found that young people with autism and LD have shown higher prevalence of mental health problems than other peers without autism (Bradely et al. 2004; Hill and Furniss 2006). Morgan et al. (2003) reported that this group, with mild to moderate LD and autism, have higher abilities and are proportionately more disabled by their autistic features and they are therefore more likely to develop mental health problems. It can be concluded that co-morbidity with autism and LD has a great effect on the prevalence of anxiety.

## **2.21. THE MANIFESTATION OF ANXIETY IN LEARNING DISABILITIES AND AUTISM**

The presentation of anxiety in individuals with LD and autism is still being explored, in contrast to the vast literature that exists for the general population and people with LD. Previous studies have drawn attention to the

association between LD, autism, and anxiety. Although, clinicians have cited anxiety as a common feature of autism spectrum disorders (Attwood 1998), the clinical picture of anxiety in children with LD is still unclear and appears more confusing (Matson et al. 1997; Bellini 2004 a, b).

The manifestation of anxiety in young people with autism and LD includes several types of anxiety, for instance social anxiety (Gillott et al. 2001; Bellini 2004; Tantam 2000), separation anxiety and obsessive compulsive disorders (OCD) (Melfsen et al. 2006; Gillott et al. 2001), in addition to specific fears or phobias (e.g. of certain sound, smells, objects, animals), resistance to change (e.g. new clothes, foods, routines), panic and emotional distress for little or no apparent reason, tenseness, shyness and irritability (Gillott et al. 2007; Brereton and Tong 2002).

Research demonstrated that children and young people with autism display higher levels of social anxiety than their non-disabled peers (Gillott et al. 2001; Bellini 2004; Tantam 2000). Literature concerning anxiety in children with autism reported that some factors are likely to be related to the high anxiety, for instance children with autism exhibiting fears and worries regarding social situations (Bellini 2004 a), the fear of possible change and of being criticized are probably related to social anxiety (Melfsen et al. 2006) .

Another form of anxiety is OCD, which is frequently found among people with LD (Gillott et al. 2001, 2007; Szymanski and King 1999; Melfsen 2006), as well as children with autism. Repetitive routines and rituals are evident in OCD and often seen in children with autism (Bejerot 2007; McDougle et al. 1995). The most common compulsion in people with LD is ordering, with handwashing, cleaning and checking rarely seen, despite their regular appearance in the general population (Cooper 1997).

However, Cooper (1997) reports a rate of 2.5% for OCD in adults with learning disability, which is higher than in the general population, and Smiley (2005) argued that obsession thoughts are hard for people with LD to

describe and, although compulsions are more readily observed, it can be difficult to distinguish them from stereotypes, tics and autism.

In terms of how young people with mild LD understand anxiety, Wilson et al. (2005) illustrate that people with LD could not discuss their understanding of mental health issues in abstract terms, but tended to use descriptive terms often linked to unpleasant emotional and physical sensations. They used words like "temper", "frightened", "fed up" and "things wrong with me", and described the physiological symptoms of anxiety and depression, such as sweaty palms and hyperventilation. Sometimes they used phrases that seemed to have been picked up from others, like "mood swings" and "in a huff".

## **2.22. THEORIES OF AUTISM AND ANXIETY**

This section reviews conceptual data on co-morbidity in anxiety and autism, and explores the theory of autism to explain relationships between anxiety and autism. There are many theories of autism; however only a few of these theories have explained the presence of anxiety. This section explores the relation between some theories of autism and anxiety. Explaining this theoretical perspective of autism may give more understanding of the nature of anxiety in autism.

### **2.22.1. Theory of mind and anxiety in autism and LD**

Theory of mind (TOM) refers to an individual's ability to attribute mental states (i.e. beliefs, desires, and intentions) to themselves and to other people as a way of participating and making sense of behaviour (Baron-Cohen, Leslie & Firth 1985; Baron-Cohen 1995; Baron-Cohen, Tager-Flusberg & Cohen 1993, 2000). People with autism show significantly poorer performance on these tests of their understanding of others' beliefs and

knowledge as compared to matched controls (Baron-Cohen et al. 1993, 2000). Based on these findings, Sigman (1998) hypothesised that children with autism may not share their subjective experiences with others. Also, children with autism consistently display impaired use of gestures and eye contact to coordinate attention with other persons in order to share one's interest with them (i.e. non-verbal joint attention (Klin, Jones, Schuttz, Volkmar & Cohen 2002)). This then proposed that children with autism spectrum conditions have deficits in their ability to understand other's problem status and are unable to contemplate or talk about their own mental status (Baron-Cohen, et al. 1985, 1989). The study of Yirmiya and Shulman (1996) reveals that autism does not involve a specific impairment in theory of mind and that theory of mind deficits are not unique to autism. However, consistent research findings (Baron-Cohen, et al. 1985 and 2000; Kleinman et al. 2001; Shaked et al. 2006) emphasise that TOM is evident in most individuals with autism, and have suggested this as a core deficit of autism.

Overall, researchers have concluded that neuropsychological and cognitive deficits characteristic of individuals with autism may influence impaired social functioning, emotional and behaviour response, and the affective development of individuals with ASD (Burnette et al. 2005) and LD (Thirion-Marissiaux and Nader-Grosbois 2008). However, the question here is whether the cognitive ability and theory of mind can explain the vulnerability of individuals with autism to develop anxiety.

Children with autism may display clinical levels of anxiety and mood disorders (Ghaziuddin et al. 1998; Kim et al. 2000; Muris and Steerneman 1998; Tantam 2000). Also, autism influences cognitive development. Recent research has investigated the developmental patterns in the interpretation of anxiety related physical symptoms and emotional reasoning by Muris et al. (2007). This study reveals that there is significant positive correlation between TOM and anxiety related interpretations.

### **2.22.2. The Central Coherence Theory**

The weak central coherence (WCC) hypothesis of Frith (1989), and further developed by Firth and Happe (1994), concerns the non-social abnormal performance in autism, indicating that core deficits in autism are due to a failure to integrate local details into a global entity. Aspects of social information processing demand this type of integration, for instance visual illusion (Happe 1996) or the meaning of context language (Happe 1997). Thus, WCC may provide a good explanation for autism (Happe 1996).

To date, the only published study examined the relation between anxiety and weak central coherence in autism, by Burnette et al. (2005) has shown that high function autism children reported more difficulty in social avoidance. Alternatively, findings indicate that no significant relations were found between the anxiety and weak central coherence measures. Thus, the hypothesis that higher anxiety would be correlated with scores indicative of weak central coherence in children with autism was not supported by the data in this study.

### **2.22.3. The Amygdala and anxiety**

It has been proposed by Brothers (1990) that the amygdala is an important component of the neural network that underlies social behaviour. A research study by Kemper and Bauman (1993) identified neuropathology in the amygdala of the post-mortem autistic brain. Owing to the abnormality of the amygdala, it has been considered to be responsible for the impairment of social behaviour in children with autism (Baron-Cohen et al. 2000; Baron-Cohen et al. 1999; Bauman & Kemper 1988).

Amaral and Corbett (2003) indicate that an important role for amygdala is in the detection of threats and mobilizing an appropriate behavioural response, part of which is fear. As a result it may contribute to anxiety in autism. Recent research by Juranek et al. (2006) investigates the association between anxiety level and depression and amygdala volume in children with autism.

Volumes for the amygdala, hippocampus, and whole brain were obtained from three-dimensional magnetic resonance images (MRIs) and anxiety scores on the Child Behaviour Checklist, carried out on 42 children with autism aged 4 to 14 years. Results indicate positive association between symptoms of anxiety / depression and amygdala volume in the autism group compared to typically developing children. In addition, Juranek and his colleagues found that anxiety is a frequently observed associated feature in autism. Anxiety and depressed symptoms were significantly correlated with increased total amygdala volume ( $P = .012$ ) and right amygdala volume ( $P = .002$ ), while there was no statistical significant correlation between with left amygdala volume.

In brief, research evidence indicates a specific relationship between amygdala and anxiety. It has been reported that amygdala may contribute to comorbid anxiety in children with autism (Amaral and Corbett 2003; Amaral et al. 2003; Juranek et al. 2006). These findings might reflect the importance of characterizing co-morbid psychiatric symptomatology in autism (Juranek et al. 2006). Thus, amygdala may contribute to abnormal fears in children with autism and increased anxiety rather than their abnormal social behaviour (Amaral and Corbett 2003).

#### **2.22.4. Social deficits**

Research has shown that the relationship between social skill deficits and social anxiety is likely reciprocal in nature. Bellini (2004) has highlighted poor social skills could lead to social anxiety, and conversely, social anxiety could contribute to poor social skills. A study by Bellini (2004 a) has indicated that 49% of the study sample of children with LD scored positive for social anxiety on the SAS-A (social anxiety scale for adolescents - self report measure of social anxiety). Findings reveal that there is a link between self reported social skills and social anxiety. According to Bellini (2004 a) this association between social function and social anxiety has been supported by previous research on adolescents without autism (Ginsburg et al. 1998; La Greca &

Lopez 1998 as cited in Bellini 2004 a). These results provide support for the association between social deficits in autism and the vulnerability to anxiety in those children with autism.

More recently, Bellini (2006) investigated the factors (social skills deficits and physiological arousal) that are associated with the development of social anxiety in adolescents with autism and social anxiety. 41 adolescents with autism spectrum disorders (including autism, Asperger's and PDD-NOS), aged 12-18 years old participated. This study used SAS-A (social anxiety scale for adolescents) to assess the social anxiety. The findings revealed that the combination of social skills deficits and physiological arousal contributes to significant social anxiety in ASD. It could be concluded that social skills deficits and physiological arousal may contribute to social anxiety in young people with autism.

According to Bellini (2004, 2006) the relationship between social skill deficits and social anxiety seems to be reciprocal in nature. Poor social skills could lead to social anxiety, and conversely, social anxiety could contribute to poor social skills. On one hand, poor social skills most probably result in some experiences of negative peer interactions, which in turn leads to increasing likelihood of fear and distress regarding social situations, and as a consequence this leads to avoidance and withdrawal from social situations [social anxiety]. This avoidance and withdrawal limits the opportunity for the individual to acquire social skills through exposure to social situations, accordingly leading to social skill deficits.

In conclusion, therefore, it can be seen that there have been a number of studies conducted to examine theories of autism in order to investigate the co-morbidity with autism and a high prevalence of anxiety. However, some theories have been found to be related to anxiety, and other theories have not supported this relationship as discussed above. This is illustrated by the following: the theory of mind was found to be significantly associated with anxiety in autism (Burnette et al. 2005). Also, amygdala was found to be

associated with increased anxiety in autism (Amaral and Corbett 2003; Amaral et al. 2003; Juranek et al. 2006). This contributes to abnormal fears in children with autism and increased anxiety (Amaral and Corbett 2003; Kim et al. 2000; Gillott et al. 2001). It is suggested that the neurobiological system in children with autism (amygdala) makes them more vulnerable to overstimulation by the social interactions of caregivers. This overstimulation may result in social withdrawal (Bellini 2006). Research indicates specific relationships between social deficits and social anxiety (Bellini 2004 a, 2006). In addition, the overly sensitive integration in children with autism was found to be attributed as a factor for increasing anxiety. On this basis, this review suggests that some theories of autism (e.g. TOM, social deficits and sensory process) are relative to high anxiety levels in young people with autism. Although research has been demonstrated that WCC is associated with autism deficits, there is no relation found between WCC and anxiety in people with autism. It is important to develop more understanding on the nature of anxiety in autism to help the prevention and intervention of this anxiety disorder.

All the above issues affect the children themselves and those around them (the family). They often cause parents a great deal of discomfort, since they are external expressions of the "strangeness" of their children (Shulman, Tidhar and Bukai 2001). Parenting a child with autism is not easy, and often requires a good understanding of the child's autistic characteristics. Thus, children and their families are also at a great risk of developing stress and facing difficulties.

### **2.23. ASSESSMENT OF ANXIETY AND MENTAL HEALTH PROBLEMS IN LEARNING DISABILITIES AND AUTISM**

The assessment of mental health problems in children and young people with LD and autism is highly challenging. Diagnosis and classification of mental health problems in people with LD is a complex process (Sullivan et al. 2007; Bailey and Andrew 2003; Hagopian and Jennett 2008). In addition

to an accurate measurement of mental health problems in this group, it also requires a valid and reliable measurement of both LD and mental health problems (Smiley 2005). The recent review of assessment and treatment of anxiety in young people with LD and autism illustrated by Hagopian & Jennett (2008) highlights the lack of assessment for those young people. This empirical review indicates that most of assessment tools are validated only for mild to moderate LD (Hagopian & Jennett 2008). The assessment of mental health problems is based on using the same classification tools to diagnose mental health problems and to diagnose autism and LD; ICD-10 (1993) and DSM-IV-TR (2000).

It is a challenge to identify anxiety in those children with LD and autism (Sullivan et al. 2007; MacNeil et al. 2009). As a result of communication difficulties, children with autism are unable to address their emotional experience accurately, and also many symptoms cannot be observed, which may lead to misdiagnosis as problem behaviour (Sullivan et al. 2007; Smiley 2005; Matson et al. 1997; Tsai 2006; Bailey and Andrew 2003). One concern when collecting information and assessing the children "s emotional problems is to use informant reports by asking parents and teachers, or asking people who know the child very well to complete these scales (Raghavan and Patel 2005). This was exemplified by Sukhodolsky et al. (2008). Sukhodolsky and colleagues reported that parent rating is a good source to identify anxiety in children with autism. Another case in point is the use of multi assessment techniques to ascertain potential cases and a way to avoid diagnostic errors (Grodén, Baron & Groden 2006; Romanczyk & Gillis 2006; Tsai 2006; MacNeil et al. 2009).

### **2.23.1. Methods of assessing anxiety**

A recent review by MacNeil et al. (2009) for anxiety in children and young people with autism included a review of the instruments commonly used for anxiety in this group. They suggest four types of anxiety assessment, which

are: clinical interview, anxiety rating scales (self-report and informative-report), direct observation and behaviourally anchored measures, and lastly physiological measures. The rating scales will be discussed in detail in the following section.

### *Anxiety rating scales*

To date, to the best knowledge of the researcher, there are no scales specifically designed to assess anxiety in people with autism. On the other hand, researchers have used measures designed for use with people with LD or the general population (Hagopian and Jennett 2008).

There are few standardized measures of anxiety designed specifically for people with LD. According to Hagopian and Jennett (2008), these measures can be classified into three categories: scales to assess a broad range of mental health problems that include subscale for anxiety, measures specifically designed and validated for anxiety in people with LD, or instruments designed originally for the general population which have been extended to use within LD .

The first category is **scales for mental health problems including the anxiety subscale**. There are a number of scales that have been developed to identify mental health problems in people with LD. These scales measure a wide range of mental health problems, including a subscale for anxiety. The following are a case in point: Reiss Scales for children's Dual Diagnosis (Reiss 1990); Diagnostic Assessment for the Severely Handicapped (DASH; Matson et al. 1991); Diagnostic Assessment for the Severely Handicapped (DASH-II; Matson et al. 1997); Assessment for Dual Diagnosis (ADD; Matson and Bamburg 1998); Aberrant Behaviour Checklist (ABC; Aman et al. 1985); the PDD-MRS scale of Pervasive Developmental Disorders in Mentally Retarded Persons is an instrument for identification of autism spectrum disorder in persons with learning disabilities (Kraijer 1997); Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson et al. 1984);

Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD; Moss et al. 1998); and Assessment for Dual Diagnosis Emotional Disorder Rating Scale for Developmental Disabilities (EDRS-DD; Feinstein et al. 1988) and Developmental Behaviour Checklist (DBC-P; Einfeld and Tonge 1995). The DASH-II scale is used with people with autism and LD by the following studies, Bradley et al. (2004) and Hill and Furniss (2006), while the DBC-P is used by Brereton et al. (2006).

However, it has been suggested that each of these may have been used in studies but, as they are all screening rather than diagnostic instruments and little work has been done on their psychometric properties, the validity of the results obtained is limited (Smiley 2005). It is important to indicate that those scales that include subscales of anxiety are limited to a few items, and will not assess the appropriate components of anxiety; therefore the anxiety assessment using those scales appears not to be accurate (Hagopian and Jennett 2008). Thus another specific instrument might be needed.

Another set of measures are **anxiety scales specifically validated and developed for people with LD**. Only a few anxiety scales have been specifically designed for people with LD. *The Glasgow Anxiety Scale for Intellectual Disability (GAS-ID)* (Mindham and Espie 2003) is a self rating scale developed specifically for anxiety. GAS-ID designed to measure three dimensions of anxiety, cognitive, behaviour, and somatic symptoms of anxiety. It is self rating scale, and is therefore more appropriate for children with mild to moderate LD, rather than severe or profound LD. This scale was used by Douglass et al. (2007). *The Anxiety, Depression, and Mood Scale (ADAMS)*; Esbensen et al. 2003) is another rating scale of symptoms related to anxiety, depression, and mania to use for people with mild to moderate LD. This instrument is not primarily for anxiety. *The Child and Adolescent Symptom Inventory CASI* is a 132-item rating scale that combines the non-overlapping symptom modules of both the Child Symptom Inventory-4 (Gadow and Sprafkin 1994, 2002) and the Adolescent Symptom Inventory-4 (Gadow and Sprafkin 1997, 1998). This is a behaviour parent rating scale

whose items correspond to the symptoms of disorders defined by the DSMIV (1994). This scale was validated with participants with PDD and autism (Sprafkin et al. 2002; Weisbrot et al. 2005; Sukhodoisky et al. 2008). Other scales for adults with LD include *The Fear Survey for Adults with Mental Retardation* (FSAMR; Ramirez and Luckenbill 2007).

The final example of instruments is **the rating scales that have been developed originally for general population** and were used for people with LD, such as the *Zung Self-rating anxiety scale* (Zung 1971). This scale has been used with people with LD (e.g. Masi et al. 2002). *Spence Children's Anxiety Scale* (SCAS: Spence 1997) is a 45-item self-report questionnaire used to measure overall levels of anxiety, as well as six specific subscales of anxiety based on the DSM-IV criteria and consistent with ICD-10 (APA 1994). This has been used with people with autism (Gillott & Standen 2004).

Clinical interviews and direct observation of behaviour have been considered as valuable methods for assessing anxiety in children and young people with LD and autism (Hagopian and Jennett 2008; MacNeil et al. 2009).

Finally, it is clear therefore that there is a need for both assessment and measurement tools which are designed specifically for this population (Sukhodolsky et al. 2008; MacNeil et al. 2009). Such instruments would need to consider autistic features, such as communication difficulties and language ability.

This highlights the need for an accurate and comprehensive assessment for anxiety in this group as this is essential for helping parents and professionals to understand children's strengths and needs, and for designing and implementing interventions. The identification of anxiety in a child with autism also creates an opportunity for management (Brereton and Tong 2002; Williams et al. 2009).

Research has suggested that children and adolescent mental health services should seriously consider dual diagnoses in this group of children with autism (Weisbrot et al. 2005). According to Valuing People (Department of Health 2001) help and support must find the way to help them be happy, successful, healthy and safe, and to work together for the wellbeing of those children as well as their families (Department of Health 2001). The following section is a brief discussion of the policy for children with LD and autism.

## **2.24. POLICY AND PRACTICE**

A number of recent government initiatives and reports have potential to improve the mental health of children with LD and autism. Owing to the increasing recognition of the prevalence of autism and its associated problems, there is an increased demand for services, including diagnosis and management (The Royal College of Psychiatrists 2004; NIASA 2003).

In England, the Valuing People is a new strategy for learning disability for the 21<sup>st</sup> century. The Department of Health (2001) acknowledges that autistic spectrum disorders often pass unrecognised and noted the importance of adequate local provision for this group. While this report was concerned exclusively with individuals with generalised learning disabilities, the subsequent implementation guidance (Department of Health 2001) explicitly included individuals with autism and Asperger's syndrome, stating that they should have access to learning disability services where appropriate (The Royal College of Psychiatrists 2004). The Department of Health (2004) emphasises that people with autistic spectrum disorders are included in the standards related to learning disabilities.

For many years the Government has been committed to develop care plans for children with autism through a number of initiatives and programmes to support families and young children and to raise the profile and importance of early years in child development. This includes Children's Fund, Sure

Start, Neighbourhood Nurseries and the Early Excellence Centres Programme (NIASA report 2003). Alongside this, the Government gives priority to children with LD and autism, developing a plan for those children with LD, for example by aiming high for disabled children and giving better support for families (2007), and delivering the core offer to families of disabled children (2008) in providing high quality services that meet their needs.

The latest Government publication “Valuing People Now” (DOH 2008) has published a new three-year strategy for people with LD [including autism] to make sure that the lives of all people with LD are improved. One of the main priorities in the Government’s document is that all people with a learning disability are people first, with the right to lead their lives like any others, with the same opportunities and responsibilities, and should be treated with the same dignity and respect. “Valuing People Now” (DOH 2008) has drawn attention to focus on not only the lives of people with a learning disability, but also the needs of families and carers.

The objectives of “Valuing People Now” (DOH 2008) are designed to serve as a framework for improving the health of all people in the UK during the 3 years (2009 - 2011) and include:

- All people with LD and their families will benefit from Valuing People.
- All people with LD and their families will have greater choice and control over their lives and have support to develop person-centred plans.
- All people with LD get the healthcare and the support they need to live healthy lives.
- All people with LD and their families have the opportunity to make an informed choice about where, and with whom, they live.

- All people and their families to have a fulfilling life of their own, beyond services, that includes opportunities to work, study, and enjoy leisure and social activities.
- People with learning disabilities should be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities.

The UK Government has delineated the policy context for children and young people with LD. The priority is to set up services for children & young people and their families that meet their needs to have a good life. Some specific provisions of children's services are related to:

- Every Child Matters (2004).
- National Service Framework for Children, Young People and Maternity Services (2004).
- The National Children's Plan (2007).
- Aiming High for Disabled Children (2007).
- Early Intervention Programme (2005).
- A better health, ensuring that the NHS provides full and equal access to good quality health care (2008).

### **Every Child Matters**

The government committed to set a plan for disabled children and young people and those with complex health needs. This is made clear in Standard 8, of the UK policy (DOH 2004), to maximise the health and well-being and achievement of all children.

### **Standard 8**

*Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives*

(DfES; Change for Children, Every Child Matters 2004; PP.5)

In brief, in the UK, 2% of the population have LD, at least 1 in 1000 of the general population have LD, and around 500,000 (1%) people in the UK have autism, with prevalence estimates approaching 10 in 1000. Children with LD and autism are at increased risk of developing mental health problems to levels of four times more than their non-disabled peers. Young people with chronic conditions diagnosed with autism, LD and mental health often face more difficulties negotiating the tasks of adolescence than their non disabled peers. Moreover, as a result of challenges in applying diagnosis criteria for anxiety in children with LD, anxiety is often misdiagnosed, leading to poor treatments (Sullivan et al. 2007; Bailey and Andrew 2003). Unfortunately, in comparison with the general population, assessment and treatment for anxiety in this group is very poor (Hagopian and Jennett 2008; White et al. 2009; MacNeil et al. 2009).

Children with LD and autism have difficulties that impact on their daily life. In addition, families with a child with autism are more stressed (Herring et al. 2006). At this point, highly specialist services are needed to support not only the child but also the family's needs in mental health problems and psychosocial interventions.

Taking all these factors into account, learning disabilities will show much higher percentage increases in the near future. The increasing number of individuals with learning disabilities presents a key challenge to their assessment and treatment in mental health services. In particular, children

and young people with LD are more likely to experience mental health problems than the general population. Two major issues need to be taken into consideration within mental health services. The first is developing early interventions and appropriate support to the individual with LD and autism. Second, it is important that children and adolescent mental health services address the family's and children's mental health needs and develop a training programmes for parents, thus providing the appropriate skills to parents and carers for the quality of life of those families and the child's wellbeing.

This research focuses on anxiety as one of the most prevalent mental health problems amongst this group. Section-II of the literature will explore psychosocial interventions for anxiety in those children and young people with LD & autism, and also discusses in detail the parent's perspective.

## **SECTION II: INTERVENTION AND PARENT PERSPECTIVES**

This section considers the literature on psychosocial interventions for anxiety in children with LD and autism, and also discusses the parent's perspective of caring for a child with autism, highlighting the role of parents in the intervention.

### **2.25. PSYCHOSOCIAL INTERVENTION FOR ANXIETY**

The intervention of anxiety in people with LD and autism parallels with that in the general population (Cooray and Bakala 2005). However, little research has investigated effective intervention options for anxiety in autism (Chalfant et al. 2007; Hagopian and Jennett 2008). These include medication and psychosocial treatment (Chalfant et al. 2007; Cooray and Bakala 2005). Psychosocial interventions form a major part of the therapy of people with LD and mental health problems (Raghavan and Patel 2005), such as behaviour, and cognitive behaviour therapy. By scoping the literature on psychosocial treatment for anxiety in children and young people with autism and LD, the lack of published research to address anxiety in children with co-morbid LD and ASD is noticeable. However, the review reveals several studies in terms of anxiety in people with LD, and other intervention studies for anxiety in ASD, including Asperger's syndrome (Table 2.4 and 2.5).

A recent review on treatment of anxiety in children with LD and autism (Hagopian and Jennett 2008) has shown that the treatment of anxiety in this group is rare compared to the general population. This review (Hagopian and Jennett 2008) identified 48 published studies on individuals with LD (mild to profound), across different age groups ranging from childhood to adulthood. These studies included people with and without autism. It is noted that 18 studies are controlled clinical case reports and 5 are controlled group studies. The majority of these studies (39 of 48) are for phobic avoidance (avoidance of particular situations or stimuli associated with anxiety or fear). This review, by Hagopian and Jennett (2008), revealed that treatment of

anxiety for the LD and autism population is rare, and limited to behavioural procedure, including graduated exposure and reinforcement as a treatment for phobic avoidance in this population. Recently, a systematic search review focused on anxiety in children and young people with autism. White et al. (2009) reported 14 studies examined interventions for anxiety, of which four studies only concerned psychosocial intervention and the remaining ten medications. In terms of the psychosocial intervention, cognitive behaviour therapy showed promise as an effective treatment for anxiety in people with ASD.

In this context, it is vital to reflect on the psychosocial interventions being used successfully among children with LD and autism, including behavioural and cognitive approaches.

### **2.25.1. Cognitive Behaviour Therapy (CBT)**

Increasingly, research evidence and reviews have demonstrated the success of applying CBT to individuals with LD (e.g. Hatton 2002; Joyce and Hardy 2003; Lindsay 1999; Kirkland 2005). CBT interventions have been used successfully in the treatment of people with mild to moderate LD presenting with a variety of problems, including depression (e.g. Lindsay et al. 1993; Hare et al. 1997), anger (e.g. Willner et al. 2002), sexual behaviour (e.g. Stenfert Kroes et al. 1997; Lindsay 1999) and social phobia (e.g. Dagnan et al. 2006) and for specific phobias (e.g. Dixon & Gunary 1986; Lindsay et al. 1988). Similarly, it has been used with children with ASD (e.g. Sofronoff et al. 2005; Chalfant et al. 2007).

#### ***Cognitive behaviour therapy and LD***

A small number of studies examined CBT particularly in relation to reducing anxiety amongst people with LD. Case studies and a case series have demonstrated the potential feasibility of cognitive behaviour therapies in

reducing anxiety amongst people with LD (Hatton 2002). This is illustrated by Lindsay et al. (1997), who identified success in applying Beck’s cognitive therapy for two case studies, and positive outcomes were maintained at 18 months follow-up. Lindsay (1999) also worked with 15 individuals with clinically significant levels of anxiety. Treatment was over an average of 23 sessions and resulted in a statistically significant reduction in self report measures of anxiety, which were maintained at 6 month follow-up.

Dagnan and Jahoda (2006) describe the specific cognitive model and associated interventions for people with LD and anxiety, and took a particular example of social phobia with people with LD. Dagnan and Jahoda suggest that cognitive behaviour therapy would be useful to apply to other anxiety presentations and to identify areas for further clinical and research development.

**Table 2.4. Intervention studies for anxiety in people with LD.**

Study	Sample	Age	Anxiety measure	Treatment duration	Type of intervention	Outcomes
<b>Lindsay (1999)</b>	15 cases with LD	N/A	Self report measures (Beck Inventory / Zung anxiety scale)	23 session	CBT	Statistically Significant improvement in reducing anxiety
<b>Lindsay (1997)</b>	2 case studies with LD	N/A	Beck anxiety inventory, self-ratings of anxiety related thoughts	N/A	Beck’s cognitive therapy	Successful of reducing anxiety
<b>Lindsay et al. (1989)</b>	50 adults with moderate to severe LD	Adult	Behavioural anxiety scale & pulse rate	12 session	Behavioural relaxation training	Effective in reducing anxiety

N/A= not applicable

## ***Cognitive behaviour therapy and ASD***

Applying cognitive behaviour therapy in children with ASD is challenging. However, there is a small number of research studies (6 studies only) investigated treatment of anxiety using cognitive behaviour treatment in the population of ASD (e.g. Chalfant et al. 2007; Sofronoff et al. 2005; Reaven & Hepburn 2003). For instance, Reaven and Hepburn (2003) described the use of CBT to treat obsessive compulsive disorder in a 7 year old female with Asperger's syndrome. The intervention was based upon the work of March and Mulle and was adapted on the characteristics of the case. In addition, this study modified parents' role to be directly involved, although in this model parents are usually involved as coaches. The findings suggest that CBT can be an effective treatment for decreasing OCD symptoms in children with an autistic spectrum disorder, with the appropriate modifications. A joint child and parent semi-structured interview (the children's Yale-Brown obsessive compulsive scale) was administered before and after treatment.

Sofronoff and Attwood (2003) show the evidence that CBT is effective in reducing anxiety in 8 to 10 year old children with high functioning autism. This study involved two intervention groups: parents and child, child only (parent received written material only), and waiting list control group. Anxiety has been assessed using the child measure "James and the Maths Test", parents' report measures of self efficacy in the management of specific behaviours related to Asperger's syndrome, and structured parent evaluation. The findings show a significant difference between intervention groups and waiting list groups. It is interesting to highlight that the involvement of parents enhanced the intervention compared to the other group intervention (children only). Moreover, the parents' feedback about the effectiveness in reducing anxiety in their children is positive. However parents involved in treatment are significantly more positive than other parents who received written material only. Another study by Sofronoff et al. (2005) demonstrates the effectiveness of a brief CBT intervention for anxiety with children diagnosed with Asperger's syndrome.

More recently, a controlled trial study of family-based CBT by Chalfant et al. (2007) examined the efficacy of CBT for anxiety in 47 children aged 8 -13 years with high functioning autism. There were two groups: the treatment group and the waiting list control group. This study used multi assessment of anxiety, including parents' interviews, self report measures, the Spence anxiety scale and the children's automatic thoughts scale. The CBT treatment is adapted from the Macquarie University "Cool Kids" programme. The parent based group CBT manual was also adapted to use with families in concurrent sessions to the child programme. The parent programme addressed anxiety education, relaxation strategies, cognitive restructuring exercises, graded exposure, parent management training and relapse prevention. The treatment was applied by therapists, and interventions took place in groups (four groups: 8-10 children per group). The results reported significant differences between pre-and post-treatment in anxiety symptoms as measured on the above reports. The majority (71.4%) of treated children no longer fulfilled diagnostic criteria for an anxiety disorder.

It is important to highlight that psychological treatments probably need some modifications in order to compensate for the language impairment of children with autism (Brereton and Tong 2002; Williams & Heslop 2005). For instance, the model of CBT needs to be applied differently for this group to take into account their cognitive impairment and support needs (Cooray and Bakala 2005; Brown and Marshall 2006).

**Table 2.5. Intervention studies for anxiety in people with autism**

Study	Sample	Age	Anxiety measure	Treatment duration	Type of intervention	Outcomes
Lehmkuhl et al. 2008	1 case with autistic disorder	12 yrs.	Parent's interview & self rating	16 weeks	CBT for OCD	Reducing symptoms of OCD
Chalfant et al. 2007	47 children with H FA	8-13 yrs.	Clinical interview & parent, child and teacher report	12 group session for 5 1/2 months	A family based CBT	71.4% no longer fulfilled diagnostic criteria for an anxiety disorders

**Table 2.5. Intervention studies for anxiety in people with autism**

(continued)

Study	Sample	Age	Anxiety measure	Treatment duration	Type of intervention CBT for	Outcomes CBT was
<b>Sofronoff et al. 2005</b>	71 children with AS	10-12 yrs.	Parent 's report via interview & 'James and The Maths Test'	6 weeks	Two intervention groups (child only & child and parent) and a waiting list for CBT	Significant decreases in child's ability to generate positive strategies for anxiety. Involving parents enhanced the usefulness of the study
<b>Cardaciotto &amp; Harbert 2004</b>	1 case with AS	23 yrs. Adult with AS	Social phobia and anxiety inventory & social anxiety scale	14 weeks	social phobia	successful in reducing symptoms of social anxiety
<b>Sofronoff &amp; Attwood 2003</b>	65 children with AS	10-12 yrs.	A child measure & parent report	6 weeks	CBT for anxiety	Significant improvement in reducing anxiety
<b>Reaven &amp; Hepburn 2003</b>	Case study with AS	7 yrs.	A joint parent.child interview	14 weeks	CBT for OCD	CBT is effective on treatment OCD

AS= Asperger's syndrome, HFA= high functioning autism, CBT= cognitive behaviour therapy, OCD= obsessive compulsive disorder.

### 2.25.2. Behaviour Therapy

Behavioural interventions, such as relaxation, appear to be effective in reducing anxiety in people with mild, moderate and severe LD (Lindsay et al. 1989; Morrison and Lindsay 1988). For instance, the work of Lindsay et al. (1989) shows that anxiety management training is effective in isolated reports. Relaxation training is used for anxiety management and its methods include progressive muscle relaxation, with Benson and Havercamp (1999) suggest that relaxation training can be a primary intervention technique for managing generalised anxiety or can be implemented as part of a total intervention treatment package (Raghavan and Patel 2005). Chalfant et al. (2007) have indicated that a number of sessions implemented relaxation as a

major part of the CBT intervention for anxiety. Lindsay et al. (1989) explored anxiety treatments for adults who have moderate and severe LD by undertaking a study based on the simplification of a technique called progressive relaxation, and the study demonstrated that behavioural relaxation training is an effective anxiety treatment.

The indications are therefore that CBT is used effectively to treat anxiety in people with LD as well as people with autism. Most of the literature on anxiety treatment focused on children and adolescents with ASD (either with high functioning autism or Asperger's syndrome) aged between 7 and 13 years old, except one case study of a 23-year old adult (Cardaciotto and Harbert 2004). The use of multiple and variable assessment of anxiety have been reported, and the majority of studies mainly used parent-report (Lehmkuhl et al. 2008; Chalfant et al. 2007; Sofronoff et al. 2005; Reaven & Hepburn 2003; Sofronoff & Attwood 2003) in addition to child and teacher-report (Chalfant et al. 2007). Other studies used clinical interviews and anxiety scales, such as the Spence anxiety scale (Chalfant et al. 2007), and James and The Maths Test (Sofronoff & Atwood 2003; Sofronoff et al. 2005).

The number of children being involved in anxiety treatment varies accordingly from one case study (e.g. Reaven & Hepburn 2003; Lehmkuhl et al. 2008; Cardaciotto & Harbert 2004) and two case studies (Lindsay 1997) to group CBT programmes (e.g. Sofronoff & Atwood 2003, Sofronoff et al. 2005 and Chalfant et al. 2007). The number of children involved in the group intervention ranged from 47 to 71 (these numbers included the waiting list group). The time span for anxiety treatment is consistently found to be 6 weeks (Sofronoff & Atwood 2003, Sofronoff et al. 2005) to 14 weeks (Reaven & Hepburn 2003; Lehmkuhl et al. 2008; Cardaciotto & Harbert 2004; Chalfant et al. 2007), while only one study extended to 16 weeks (Lehmkuhl et al. 2008).

It has been recognised that most intervention studies for anxiety focus on cognitive behaviour therapy. Additionally, a great deal of attention has been given to children with either Asperger's syndrome or high functioning autism (table 2.5.). However, little research has been carried out on anxiety treatment for children with autism and mild to moderate learning disabilities, and further research addressing the anxiety in a group diagnosed with LD and autism is required.

In conclusion, the above review clearly highlights the limitations of intervention for anxiety in children and young people with autism or people with LD to the implication of CBT interventions. Although it is effective, further research is needed to investigate whether other forms of intervention might be more appropriate for anxiety across all types of autism disorders (Chalfant et al. 2007) and to examine different intervention strategies appropriate for children with LD (Raghavan 1998).

## **2.26. PARENTS' PERSPECTIVE AND INTERVENTIONS**

### **2.26.1. Understanding nature of caring**

Parenting a child with LD and autism is quite challenging and daunting for parents (Diggle et al. 2008). Those parents face a larger number of care giving challenges in raising their children (Diggle et al. 2008; Buckley 2002; Matson et al. 2009; Plant and Sanders 2007), particularly in the early lives of their children when they often feel most vulnerable (Buckley 2002). Many parents face problems when their children are first diagnosed with LD or ASD. Most parents become distressed when they are informed that their child has autism (Randall and Parker 1999). Moreover, many of these parents have to provide, in addition to the usual general care, a much more intensive level of care, such as structuring their child's daily routines, creating opportunities for socializing, daily activities and further education, and providing companionship (Portway & Johnson 2005). Autism spectrum

disorder is a lifelong condition. Having a child with autism requires additional care in their day-to-day life relative to typically developing children (Plant and Sanders 2007). Research shows up to 80% of severely LD children aged 12-14 years old need help with self-care e.g. eating, washing, dressing, and going to the toilet, and the majority of those live at home with their parents (DOH 2004). This often reflects more stress of parenting those children (Herring et al. 2006). Furthermore, those children with LD and autism are more prone to experience additional serious challenging behaviour, and emotional and mental health problems as mentioned previously. In particular, the association between autism and LD results in increased vulnerability to risk factors for mental health problems. This can lead to more stress for parents and may affect the family quality of life. Parental stress has been reported as part of the caregiving experience for parents of children with learning disabilities (Grant et al. 1998).

Parenting a child with LD and autism may yield some additional stress domains. These include the fact that many children with LD need additional support and help throughout their lives (Department of Health 2004). Also, parents experience social isolation parents of children and young people with LD and autism probably experience a lack of welcome in the public places. Moreover, families' social interaction may be decreased due to their child's challenging behaviour (Koergel 2000; Neece and Baker 2008). Due to a lack of formal and informal support, parents may also have a problem in finding the right form of care, health services and leisure opportunities for their child (Department of Health 2001; Kenny and McGilloway 2007). Additionally, many parents are stressed about the child's future and their adult life (Department of Health 2001; Kenny and McGilloway 2007; Tehee et al. 2009). Parents can feel undervalued by public services, and lack the right information and enough support to meet their lifelong caring responsibilities (Department of Health 2001). Other potential stressors may include parents of children and young people with LD have higher costs as a result of the child's disability coupled with diminished employment prospects. The estimated annual cost of bringing up a child with LD is three times greater

than non-disabled children (Department of Health 2004). Other stress sources may include their housing needs may not be adequately met (Department of Health 2001), and parents are often worried about the adult life of their children. Young people with LD often leave school without a clear route towards a fulfilling and productive adult life (Department of Health 2001; Williams and Heslop 2005). Also, the care demands on parents, multiple appointments with services, and lack of childcare affecting their ability to work are all important factors. As a result, mothers of children with LD are less likely to have paid employment than other mothers and fathers' employment (Department of Health 2004).

Additionally, the majority of children and young people with LD and autism are at a high risk of developing additional mental health problems, such as anxiety, depression, OCD, or attention deficits (Bradley et al. 2004; Hill and Furniss 2006; Brereton et al. 2006; MRC 2001, Kim et al. 2000; Howlin 2000). It has been suggested that children with LD's behaviour problems have a major effect on parents' mental health and contribute to parental stress (Neece and Baker 2008). A child experiencing mental health problems may have an added impact upon parent's ability to undertake caregiving responsibilities. Consequently, parents become more burden of caring their child (Plant and Sanders 2007). This makes the parent's responsibilities more complicated, and may have a negative impact on the family well-being (Emerson and Hatton 2007).

The above factors all combine to place tremendous stress on the families of children and young people with LD and autism which can have a negative impact on the children and young people and the wellbeing of the family.

### **2.26.2. Impact on the family**

It has been shown that a child with autism has considerable impact on the life of the parents. Caring for a child with LD and autism results in parents being

more likely to develop mental health problems, such as stress or depression, compared to other parents (Heiman 2002; Koegel 2000; Hastings et al. 2006; Heiman and Berger 2008; Diggle, McConachie and Randle 2008). Research evidence indicates that parents of children with autism report high family stress more than parents of other developmental disabilities (Hasting and Johnson 2001), and parents of children without disabilities (Sivberg 2002). A comparison study by Weiss et al. (2002) investigated the role of hardiness and social support in the development of stress (e.g. anxiety, depression) for mothers of children with autism, mothers of children with LD and mothers of children without disabilities. Social support is assessed by the interpersonal support evaluation list, and hardiness is assessed by the Hardiness list. The results indicate that mothers of children with autism experience more negative effects of stress than mothers of children with LD, or children without disabilities. The findings also report the impact of social support for parents to cope with stress.

Research concerning mental health and stress in relation to parenting a child with autism indicates that mothers are significantly more stressed by their child's autism (Herring et al. 2006; Tehee et al. 2009; Emerson et al. 2006). Herring et al. (2006) reveal that a child's emotional and behavioural problems contributed significantly to mother's stress. Parental mental health was evaluated with the General Health Questionnaire, and parenting stress was measured with a self-report stress thermometer visual analogue scale. The findings also indicate that fathers are less stressed than mothers, regardless of whether their child had an ASD or not, and in relation to parenting their child. This is consistent with the work of Tehee et al. (2009) which examined the factors that contribute to parental stress, assessed by The Perceived Stress Scale. Tehee et al. (2009) revealed that the mother is significantly more stressed than the father while providing care to a child with autism. Additionally, research evidence indicates that mothers of children with LD reported lower levels of self-esteem, happiness, and self-efficacy than mothers of children without LD (Emerson et al. 2006). It may also have significant effects on family functioning and on family relationships, and may

create some changes in the family's routines (Heiman and Berger 2008).

Children and young people with LD and autism may have a serious impact on the family. However, parents try to maintain their life and try to develop a routine life environment (Heiman and Berger 2008), and also adopt coping strategies (Pakenham et al. 2004; Gray 2006; Grant et al. 1998; Grant and Ramcharan 2001; Kenny and McGilloway 2007) in order to support their children and increase wellbeing.

Previous research has documented the need for additional social support for parents of a child with LD, and stresses the importance of developing awareness and intervention programmes to facilitate parents' coping abilities and their family interactions (Heiman and Berger 2008). It is important to realise that supporting parents is helpful to relieve parental stress and family wellbeing (Tehee et al. 2009; White and Hastings 2004).

### **2.26.3. Impact of anxiety**

Overall, anxiety in children, as any other disorder, can have negative impact upon the child and the family. In relation to the child, anxiety probably affects the child's life. For instance, shyness results in difficulties to make friends, meeting new children, and joining in activities (Rapee et al. 2008). Research has indicated that the emotional and behavioural problems of children are one of the most important effects on family wellbeing (Herring et al. 2006). Researchers are encouraged to promote child mental health, focusing on family as centred ways of working with children with special needs (Buckley 2002). It is important to recognize that parents of children and young people with LD and autism can have rewarding lives, as many already do. Therefore, there is a great need for appropriate interventions to help parents deal with the child's mental health problems. As a result, improved provision for parents can help them to live as ordinary a life as possible (Department of Health 2004).

Currently, no published research is focused on anxiety intervention and coping strategies for anxiety in children and young people with LD and autism (Hagopian & Jennett 2008), in particular research that provides parents, children and young people with effective management strategies for anxiety. This highlights further research is demanded in interventions and training for families caring for a child or young people with LD & autism. The following discussion explores different aspects of the research, and involving parents in intervention.

## **2.27. INVOLVING PARENTS IN INTERVENTIONS**

Over time, it has been consistently recognised that parents are a critical component of interventions (Schopler and Reichler 1971). There is growing research interest in involving parents of people with LD in interventions. Several studies have provided support for the importance of involving parents in intervention in the population of people with autism and LD (e.g. Reaven and Hupburn 2006; Sofronoff and Attwood 2003; McConachie and Diggle 2007; Heiman 2002). Studies have also shown that involving parents is important in managing anxiety in typically developing children (Leong et al. 2009; Barrett, et al. 1996; Cobham et al. 1998). Furthermore, research suggests that parents of children with autism play an essential role in the intervention process (Diggle et al. 2008; Ozonoff and Cathcart 1998). The family has been considered as a main source of support for their children throughout the child's lifetime (Heiman and Berger 2008; Buckley 2002). It has also been found that involving parents in the intervention is useful in strengthening families' capacities to meet the needs of the child (Wang 2006). Research suggests that it is important to empower parents to help their children (Williams and Heslop 2005).

Research addressing issues concerning parental management strategies for children and young people on the autistic spectrum for mental health problems is limited. However, this section discusses general aspects and different forms of parents' involvement in interventions with their children with

LD and ASD. A variety of parent training programmes have been developed to address different problems in children with LD and autism. Recently,

Matson et al. (2009), in a review paper of trends of parents' training for children with developmental disabilities, indicate that those methods of parents training vary widely from group to individual parent training, manuals, curriculums, video and live instruction. The following are examples of this:

### ***Training and workshop***

A number of intervention programmes empower families to work collaboratively with professionals. This type of program trains parents as therapists or co-therapists. For example, the intervention by Sofronoff et al. (2005) formed two "parent groups" and therapist trained parents to work as co-therapists in all components of the intervention. This training method has frequently been carried out in groups. The number of parents involved in group interventions has varied from 23 parents (Sofronoff et al. 2005) to 49 parents (Clark et al. 1982). Other interventions trained a single parent (Reaven and Hepburn 2003; Cardaciotto and Herbert 2004). Other parents have been trained individually with practitioners (Plant and Sanders 2007).

Research shows that parent's training knowledge is the most important factor associated with a positive outcome (Clark et al. 1982). Chalfant et al. (2007) report that there are two different ways of involving parents in applying CBT-like strategies, either to teach some strategies for reducing anxiety to parents and then in turn parents can re-teach the skills to their children, or by teaching parents how to manage their own stress, and as a result they can cope better with their child's anxiety.

Most recently, research attempts to recognise the importance of empowering parents in interventions. Research has aimed to investigate whether more intensive parental involvement would increase the child's ability to manage anxiety: Sofronoff and Attwood (2003) compared two forms of intervention for anxiety in children with Asperger's syndrome, one in which only children participated, and a second in which parents were taught all strategies and given information in the same manner as children. Treatment involved 6

weekly group sessions and was compared with two groups (children only and waiting list). The findings indicate significant differences between the two intervention groups and the waiting list group, to suggest parent involvement as beneficial. The combined child and parent group demonstrated improvement compared with the group which involved children only. The feedback about the programme and its effectiveness on reducing the children's anxiety from those parents involved in the anxiety treatment is significantly more positive than from parents who were not involved.

Some researchers modified CBT interventions to treat anxiety in children with ASD (as discussed previously). For instance, Reaven and Hepburn (2003) modified the CBT programme for parents to be actively involved in the intervention, attending every session and maintaining active involvement throughout treatment. Chalfant et al. (2007) indicated that family-based CBT for anxiety is successful. Parents' involvement included completing daily homework assignments. The findings are consistent with the literature of applying CBT for anxiety in typically developing children, which has more successful results when parents are actively involved (Leong et al. 2009; Cobham Dadds and Spence 1998). Likewise, the work of Sofronoff & Attwood (2003) and Sofronoff et al. (2005) demonstrated that involving parents in the intervention for anxiety enhanced the usefulness of the CBT intervention, reporting a significant increase in the child's ability to generate positive strategies in an anxiety situation.

One behavioural parent training programme, known as Stepping Stones Triple P (SSTP) by Plant and Sanders (2007), employed 74 families of children with autism and other developmental disabilities. Parents were trained individually with the practitioner on a weekly basis for 60-90 minutes. Interventions were assessed on parent-report measures and videotaped home observations. Findings suggest that these interventions resulted in more adaptive parenting skills and increased parental competence, and were maintained at a one year follow up.

### ***Home based programme***

Several studies attempt to teach parents how to work with their young child with autism in the home setting, such as treatment and education of autistic and communication handicapped children (TEACCH), Early Intervention Behavioural Intervention (EIBI), and the Son-Rise programme. For instance, a study by Ozonoff and Cathcart (1998) implemented the TEACCH programme by training a group of 11 parents of children with autism aged 2-6 years to implement the programme at home, and those parents were compared with a control group of 11 parents. The mean number of treatment sessions lasted 10 weeks. This study concerned cognitive, academic and prevocational skills essential to later school success. Children in the treatment group reported significant improvement relative to the control group.

Similarly, research suggests that children with ASD may improve by receiving the parents management EIBI programme (e.g. Bibby et al. 2002; Sheinkopf and Siegel 1998; McEchin, Smith & Lovass 1993). In a study by Sheinkopf and Siegel (1998), US children received the parent's management intensive intervention, which focused on behavioural treatment. This programme was implemented by 11 parents of children with autism with the assistance of community-based clinicians, and lasted 16 months. The results indicated that intensive home based behaviour interventions can be implemented successfully, without the direct support of an academic centre.

Smith et al. (2000) carried out research to apply the UCLA treatment model developed by Lovaas and colleagues (Smith and Lovaas 1998). Six parents with children with autism, and therapists, have been trained by professionals in ABA techniques to develop a treatment plan for the child. Parents and therapists received six one day workshops for early intervention for young children with autism for over a five month period, with additional consultations for the next 2-3 years. Parents who were involved in treatment rated the treatment very positively at follow-up.

Another type of home-based parent training is the "Son-Rise programme". This is a training comprehensive programme of treatment and education designed to help families and caregivers enable their children to improve in all areas of learning, development, communication and skill acquisition. It offers highly effective educational techniques, strategies and principles for designing, implementing and maintaining a stimulating, home-based, child-centred programme. The home-based setting has been recognised as one of the most evidence-based psychological interventions (DOH 2001, NICE 2002).

#### ***Training materials (or parents' information pack)***

This is another facet of methods based on providing parents with principles to help understand psychosocial problems and learn ways to cope with the problem (NICE 2007), as well as providing structured written materials for teaching parent skills to caregivers of children with LD (Matson et al. 2009). In a study which empowered parents, Sin et al. (2007) developed carer information packs including information around understanding mental illness, and practical advice on what is helpful in caring for someone with first episode psychosis, compiled by carers themselves. Additionally, this included homework between sessions so that parents can apply what they have learnt to their own family's situation.

This form of parents' involvement was established a long time ago, as Heifetz (1977) used structured training materials to teach parent skills to caregivers of children with LD. This 20 week programme focused on research by Heifetz (1977) on behavioural principles to enhance the self-help skills of parents of children with LD, and also challenging behaviour and language skills. This study reported that simply reading the manuals was as effective as using manuals and therapist training (as cited in Matson et al. 2009).

In addition, practitioners may provide information, such as a parents' workbook as a training material or as a part of the active training. An example of this training is a study by Plant and Sanders (2007) where parents were provided with a workbook which helps to set and monitor their own goals. Furthermore, a daily diary is also considered an important component of training materials and has been used to record the practice and outcomes from using training programmes by parents (Chalfant et al. 2007).

Video-based courses are another training material implemented for parents through the "Parent plus programme". This consists of two videos and a facilitator's manual. The manual contains directions on running the programme, session plans and handouts for parents. This programme is designed for typically developing children and adopted by Quinn et al. (2007) to use with preschool children with developmental disabilities (e.g. LD & autism), as it helps parents manage and solve children's behaviour problems. Quinn et al. (2007) compared 22 parents in the treatment group with 19 waiting list controls. Parents who participated reported satisfaction with the programme. Fifty percent of treated children showed clinically significant improvement. These gains were maintained at 10-month follow-up.

Research shows that programmes based on presenting just training of behavioural principles / materials can be almost as effective as live training in establishing parenting skills (Matson et al. 2009). Providing structured training materials (parent information package) has been considered in turn in the current research by providing parents and carers with an information pack, and a diary.

### ***Informal support***

In addition to the formal intervention, parents may use informal support to help their children and maintain their life. Some parents attempt to gain other

experience, seeking advice from nuclear family members, grandparents, and other relatives (Heiman 2002), while the majority of parents benefit from support provided by the education system, voluntary organizations or other special public or private services (Heiman 2002). It has been suggested that parents also gather information about different intervention strategies with their children with LD and autism (Heiman and Berger 2008).

A recent study by Green et al. (2006) has identified 111 treatments used by parents, and those treatments are grouped into 11 categories. The findings indicate that the most used treatment categories are standard therapies and treatment focusing on skills training, especially those based on the principles of ABA. Results from this study (Green et al. 2006) indicate that parents of children with autism reported using an average of seven different treatments. The most commonly used treatments by parents of children with autism are speech therapy, visual schedules, sensory integration, applied behaviour analysis and social stories.

In a study by Reaven and Hupburn (2006) suggested the parents' role in intervention for their children with autism is really important. According to Reaven and Hupburn (2006) the parent's role in anxiety interventions involves:

- Teach parents to reward courageous behaviours and extinguish excessive anxiety in their children;
- Increase parental awareness of their own anxiety symptoms and the extent to which they may play a role in the development and maintenance of anxiety symptoms in their children;
- Teach parents to model effective problem-solving and protective responses when they experience their own anxiety symptoms; and
- Teach both parents (if possible) to work together as a couple in their child-rearing practice (Reaven and Hupburn 2006; PP. 75).

The literature clearly suggests two concerns in terms of anxiety intervention and involving parents. One is that the research that is available to date has focused on CBT interventions for anxiety on specific group of children with high functioning autism or Asperger's or LD, and no research intervention is available for anxiety in children and young people with LD and autism. The other concern is regarding parents' involvement. Research that involved parents in interventions is primarily focused on improving cognitive and academic skills for children with autism (e.g. ABA), particularly behaviour therapy and applied behaviour analysis (Matson et al. 2009). Many parents are implementing treatments that are primarily aimed at teaching new behaviour; however, it did not indicate what particular skills were being targeted. Further research is needed of practical management strategies for the child's mental health problems to be implemented by parents (Green et al. 2006; Matson et al. 2009).

Additionally, it seems that most of the programmes run by parents focus on young children (preschool age), such as early intervention for autism and behaviour intervention (e.g. Plant and Sanders 2007; Quinn et al. 2007). Research studies concerning the empowerment of parents of children with LD and autism in interventions has presented different formats for parents' involvement in treatment in general, such as home-based programmes, providing parental workshops training parents as therapists, and providing training materials.

Research on caregiving for children and young people with disabilities has highlighted the valuable impact of involving parents in interventions on the whole family. Many parents implement intervention strategies and home-based treatment programmes (Green et al. 2006; Hastings and Johnson 2001; Sheinkopf and Siegel 1998), but less is known about management strategies for anxiety, and their effectiveness. Further research needs to focus on the available management strategies for anxiety in children with LD and autism.

Although parents, clinicians and researchers have drawn attention to the impact on the family of a child with autism, only a few published studies have examined this domain. A recent study (Heiman & Berger 2008) examined the family support of parents of a child diagnosed with Asperger's syndrome and parents of a child with LD, which were then compared to other parents of children without disabilities. Heiman & Berger (2008) emphasize the need for effective programmes of intervention for parental support, and encourage the efforts to help parents with a child diagnosed as having autism or LD to develop and employ more adequate coping behaviours and to enable parents to better meet both their own needs and those of their children.

Grant et al. (1998) indicate that the majority of caregivers can give better care than anyone else. Moreover, it suggests that "*services have many things to learn from family caregivers*" (PP. 46). Accordingly, professionals will benefit from parents' experiences in letting them assist other caregivers to deal with their children. However, less is known in terms of parents' management strategies for children with LD and autism. One of the main purposes of this research is to develop parental management strategies from parents' experiences.

Even though many studies have reported the importance of parental involvement in implementing intervention strategies for children with LD and ASD, there have been few attempts at empowering parents in interventions for children with autism. The research that is available to date has mainly focused on early intervention for autism (Bibby et al. 2002; Sheinkopf and Siegel 1998; McEchin, Smith & Lovass 1993) or improving behaviour (Sheinkopf and Siegel 1998) and the majority of, if not all, these studies are for young children (preschool aged 2-6 years).

There is increasing research evidence to demonstrate high levels of anxiety in individuals with autism and LD. Despite this, there is a lack of published evidence focussing on parental interventions for anxiety in children and young people with autism and learning disabilities. Further research

concerning the parents' management strategies for anxiety in children with autism is required. Research should consider dealing with the child's emotional problems as an important area where parents require help. More parent management intervention research into mental health problems in children with LD and autism is greatly needed. Having the appropriate management strategies for child's mental health problems can have a mutual effect on the child coping with his difficulties and on parents by developing management skills in addition to reducing parental stress. In turn it is important for the wellbeing of the whole family.

## **2.28. CONCLUSION**

This review of the literature has outlined a number of issues in relation to children and young people with LD and autism as well as their families. Research evidence has indicated that co-morbidity with LD and autism results in an increased risk of mental health problems. Anxiety is one of the most prevalent disorders in children and young people with LD and autism. Given the high co-occurrence of anxiety in children with autism and LD, anxiety may cause considerable distress and interference with the child's daily activities (Muris and Steernman 1998; Bellini 2004 a) as well as family dysfunction or parental stress (Hastings et al. 2006; Herring et al. 2006; Tehee et al. 2009). To date, no published studies have documented the efficacy of parental management strategies for children with LD and autism as well as co-occurring anxiety. A primary purpose of this research was to develop and implement management strategies for anxiety for children and young people with LD and autism.

The research in children and young people with autism and LD, addresses the need for parental support in everyday life. This thesis explores involvement of parents in the intervention programme, as derived from literature evidence (as discussed in sec. II). A great deal of research literature indicates that involving parents in interventions has been

demonstrated to improve child management skills (Leong et al. 2009; Barrett 1998; Cobham et al. 1998; Croom 2000), and found to be particularly important for families of children with LD and autism. It has been shown that there is not a great deal of research about the parent's management on a day-to-day life basis in families who have a child with LD and autism and having anxiety.

It has been suggested that the work of families continues to be seriously underestimated and undervalued (Grant 2008). A better understanding of what is happening in everyday life in terms of these management strategies needs to be explored. Although there is relatively good literature supporting the effectiveness of psychosocial interventions e.g. cognitive-behavioural treatment (CBT) of anxiety symptoms in children with autism and LD (Dagnan et al. 2006; Linsay 1997), to date no published studies have documented the efficacy of a parental intervention for anxiety, particularly in this group of children diagnosed with LD and autism. Previous research has documented that there are some effective psychosocial interventions to manage anxiety. However, these interventions were implemented almost exclusively by trained professionals. Moreover, modifications for the interventions such as CBT anxiety intervention programmes were adapted for people with autism, and are not developed initially for children with autism.

According to this research review of the literature on the intervention, in general it revealed that involving parents in interventions enhances children's functioning (Smith et al. 2000) and can improve general family harmony (Koergel 2000). To this end, the researcher suggests to empower parents to help their children managing their mental health problems. On one hand they need to be provided with more effective strategies dealing with their children's difficulties. On the other hand, they have demonstrated their great influence they have when involved in the treatment process, but also they have been considered the most appropriate individual to experience the problem with the child. Indeed, further work into parents' consultation and

empowerment in interventions for young people with LD is in demand (Sin et al. 2007). Researchers suggested that there is a great need for parents caring for children with LD to be involved in interventions for their children (Matson et al. 2009; Matson et al. 1997; Mahoney et al. 2004; Sin et al. 2007). On this basis, it is important to develop additional research with more focus on developing intervention for that group.

Finally, as highlighted by the literature, existing research underlines the potential support of both parents and children. It has been proved that there is limited research which has been carried out to explore parental management of intervention strategies for anxiety in children with autism and LD. In particular research which involves supporting parents to manage their children's anxiety. The limitations of the intervention mentioned above for anxiety in young people with LD and autism indicate that researchers need to explore interventions for anxiety. It is important to consider research which aims to directly fill gaps in existing literature. This motivated the researcher to focus on anxiety in this research, to find out how we can help children with LD and autism by supporting their parents. Thus, this research concerns anxiety in a group of children with mild to moderate LD and autism. The primary purpose of this research is to identify anxiety and develop parental management strategies for anxiety in children and young people with LD and autism. In order to explore the management strategies of anxiety in children and young people with LD and autism, more formal and systematic methods for measuring the various goals becomes a necessity.

### **AIM OF THIS RESEARCH**

The aim of this research was to develop, implement and evaluate a parental programme of management strategies for anxiety in young people with LD and autism, with the following objectives:

1. To screen for mental health and anxiety amongst young people with LD and autism.
2. To identify everyday strategies that parents and teachers use to manage anxiety in children and young people with LD and autism.
3. To develop a programme of management strategies in managing anxiety for young people with LD and autism incorporating views of parents and health professionals.
4. To implement and evaluate the programme of management strategies with a small group of parents of young people with LD and autism.

## ***CHAPTER 3: METHODOLOGY***

### **3.1. INTRODUCTION**

This chapter outlines and describes the methodological design of this research, the rationale for using this particular method and the participation criteria. In addition, it also outlines the participants' characteristics, data analysis and ethical considerations.

It is suggested that children and young people with LD may experience symptoms of anxiety at a greater level than the general population. Furthermore, co-morbidity specifically of autism may also make the children and young people with LD more susceptible to anxiety. However, little is available in relation to the prevalence of anxiety in people with mild - moderate LD and autism. Experiencing significant levels of anxiety can be disabling for young people with LD and autism, resulting in negative consequences for young people and their families. Due to these issues the family is more likely to reach crisis point (Weiss 2008). Mental health problems and anxiety often cause more distress to caregivers than core autism and LD (Hastings et al. 2006; Lecavalier et al. 2006). Research shows that parents of children with autism are more likely to be stressed or depressed compared to other parents (Heiman 2002; Koegel 2000; Hastings et al. 2006; Heiman and Berger 2008; Diggle, McConachie and Randle 2008). Identifying anxiety in those children and young people has considerable implications for treatment and the provision of services (MacNeil et al. 2009).

The first aim of this research was to identify the prevalence of anxiety in children and young people with LD and autism. The second aim was to develop, implement and evaluate a programme of management strategies for anxiety. Thus, this research focuses on assessment of anxiety and

management of children's and young people's anxiety through the support of parents.

Parents of children and young people with LD and autism play a vital role in the child's life. Autism intervention literature has documented the potential role of involving parents in interventions. A study by Heiman (2002) highlights the importance of social resources and support, and the need for effective programmes of intervention. McConachie and Diggle (2007) emphasise the parent's involvement in interventions:

*"The involvement of parents in implementing intervention strategies designed to help their autistic children has long been accepted as helpful. The potential benefits are increased skills and reduced stress for parents as well as children"*

(McConachie & Diggle 2007; PP. 120)

Research has consistently shown the importance of parents' involvement in interventions for their children and young people. However, there is little published research attempting to develop parental intervention that addresses anxiety in children and young people who are diagnosed with both LD and autism. Also, there is very little research available on supporting parents managing their children's anxiety. Almost all published studies in this area address psychosocial intervention (e.g. CBT) (Lindsay 1999; Reaven and Hepburn 2003; Sofronoff and Attwood 2003; Sofronoff et al. 2005; Chalfant et al. 2007). Involving parents will be particularly helpful to increase parents' skills and management strategies to use in day to day life and to reduce and cope with anxiety. Thus, the theme of this research is identifying the prevalence for anxiety and management strategies for parents to help children cope better with their anxiety and related behavioural issues.

This research focuses on empowering parents to help their children and young people through developing and implementing parental management

strategies. One of the primary aim of this research was to develop and

implement a programme of parental management strategies for anxiety in children and young people with LD and autism.

In order to identify the prevalence of anxiety and gain parents' experiences of managing anxiety in their children and young people with LD and autism, mixed methods of quantitative and qualitative approaches were considered. The following section will discuss the rationale for selecting this method.

### **3.2. METHODOLOGICAL APPROACHS**

A combined approach including both quantitative and qualitative methods was employed in this research as well as "triangulation". The rationale of using a mixed approach of the quantitative and qualitative methodology was due to the nature of the research objectives. This research looked at a different inquiry component at each stage. In the first study, a quantitative research approach was used to identify the prevalence of anxiety in children and young people with LD and autism. In the second study, qualitative interviews were used to explore anxiety management strategies used by parents, carers and teachers. In the third study implementing the Calm Child Programme, a triangulation approach quantitative and qualitative method was employed. 1

The reason for using an integration of quantitative methodology and qualitative methodology in this study, instead of using one methodology, was to best understand a research problem (Creswell 2009). Using mixed methods integrates the strengths of each method, as one method can enhance the other and allows for greater creativity and adaptability in the research (Morgan 1998). Moreover, the mixed methods approach is advantageous because it can result in well validated and substantiated findings (Creswell 2009). However, comparing the results of two analyses using data of different forms can be difficult. This method requires great effort and expertise to adequately study the phenomenon (Creswell 2009).

The triangulation approach was applied in the first study of this research using two scales to assess the anxiety, as well as in the third study by using mixed quantitative and qualitative methods. Triangulation entails the use of more than one method, but may also combine qualitative and quantitative methods to provide complementary information (Moris and Copestake 1993; PP. 49). Denzin (1978) defines triangulation as “the combination of methodologies in the study of the same phenomenon” (PP. 219 as cited in Denzin & Lincoln 2000). Jick (1979) illustrates that this triangulation was not only used to examine the same phenomenon from multiple perspectives but also to enrich our understanding by allowing for new or deeper dimensions to emerge. There were several reasons for using this approach for this research. Triangulation allows obtaining further information about the same phenomena. This research is seeking insight on the implementation of a parental management programme for anxiety. This was useful to evaluate the impact of using management strategies with parents through using standardised rating scale and conducting a focus group. The mixed methods approach was employed in order to broaden understanding by incorporating both qualitative and quantitative methods.

Furthermore, using this methodology, where quantitative and qualitative approaches were integrated, increased the efficiency of analysing the data. For instance, in a quantitative study, the interpretation of statistical analyses may be enhanced by a qualitative narrative account. Thus, the quantitative results of the GAS-ID are enhanced by the results of the focus group to evaluate the Calm Child Programme.

To achieve the research objective: screening for anxiety amongst children and young people with LD and autism, the quantitative method was used. Quantitative methodology is particularly suited for screening and identifying participants.

The rationale of choosing a standardized rating scale was for several reasons: this is often the easiest way of retrieving information from a large

set of people (Robson 2002). Furthermore, quantitative methods give a high amount of data standardization (Robson 2002). This study aims to screen large numbers of the population. Therefore, this approach allows involving a greater number of subjects, and enhancing the generalisation of the results.

The qualitative methods used in this research include semi-structured interviews and focus groups. The interviews aim to explore and identify parental management strategies to develop a parental Programme of anxiety management strategies for children and young people. Focus groups aimed at evaluating the Calm Child Programme. A qualitative approach was chosen for a variety of reasons:

First, according to Polkinghorne (2005; PP.139) “the experiential life of people is the area qualitative research methods are designed to study”. Data collection must “take account of the particular characteristics of the human experience” (PP. 139). Furthermore, qualitative research allows researchers to get at the inner experience of participants (Corbin and Strauss 2008). Thus, qualitative methodologies such as interviews and focus groups are particularly suited for studying, describing, clarifying and understanding subjective human experiences or “lived experiences” (Polkinghorne 2005; Schwandt 2001; Streubert & Carpenter 1999). As Schwandt (2001) so eloquently puts it “qualitative inquiry deals with human lived experience. It is the life-world as it is lived, felt, undergone, made sense of, and accomplished by human beings that is the object of study” (PP. 84).

Second, Bloor (2004) illustrates that “qualitative research techniques, with their capacity for rich description, are favoured techniques for research focused on everyday work practices” (PP. 307). Glesne (1999) states that “qualitative researchers seek to make sense of personal stories and the ways they intersect” (PP.1). This research seeks to gain insight regarding parental perspectives of day-to-day life. These will help to build up stories of management strategies.

Third, qualitative research can also be described as process oriented. Palys (1997) states that research should “unfold and evolve as more and more is understood about the phenomena” (PP. 297). Considering the sparse literature available about parental management strategies of children’s anxiety, it is difficult to create a hypothesis regarding parental responses. A qualitative research methodology offers the flexibility to study emerging themes and unpredictable information. The goal of this strategy was to have an opportunity to go into greater depth with individual participants, furthering the exploration of the research objectives.

The advantage of using interviews for qualitative methods for this research was based on the following reasons: interviews are carried out for descriptive purposes, thus providing information about the distribution of a wide range of people characteristics” and the relationship between such characteristics (Robson 2002). Another view is that the researcher can mould the interaction via the interview in order to obtain in-depth information about phenomena (Parahoo 1997). When someone has actually faced a situation of the type of disorder, his / her response in the interview is likely to be more reliable (Silverman 1993). This research aims to gain insight and perception in terms of management strategies that parents use. Parents’ responses will reflect these perceptions. Moreover, in the individual interview the researcher can succeed in creating a good relationship with the interviewees (parents) and that will improve the quality of the answers (the parents experience of managing the child’s anxiety) (Aldridge & Levine 2001).

Another qualitative method used in this research was a focus group. The purpose of conducting the focus group was to listen and gather information from the participants in relation to implementing anxiety management strategies. There are many advantages for choosing a focus group in this research. These can be exemplified as follows:

DiCicco-Bloom & Crabtree (2006) state that “focus group interviews usually take the form of group interview, where multiple participants can share their

experience or knowledge about a specific subject” (PP. 315). According to Kitzinger (1995) this is an appropriate method to discuss open questions and focus on the participants, enabling them to explore issues of importance in their own way by using language and social interactions to which they are accustomed. This research seeks to gain parents’ insight regarding implementing management strategies with their children.

This is useful to enable parents to explore and describe implementing the strategies in their own language. Focus Groups enable the researcher to gain a range of different views and experiences in an economically viable way (Jackson 1998; Sim 1998; Curtis and Remond 2007). Moreover, the group dynamics help in focusing on the important topics and it is fairly easy to assess the extent to which there is a consistent and shared view (Robson 2002). The advantage of group work is that all participants can be supported by their peers and whereas there is the potential for group acquiescence, at least it is more likely to be the group as opposed to the interviewer. These encourage participants to share their experiences and views of management strategies and support each other.

In addition, participants tend to enjoy the experience. According to Robson (2002), participants are empowered and able to make comments in their own words, while being stimulated by thoughts and comments of others in the group. This research seeks participants’ feedback of using management strategies. It might be that each parent used strategies in a different way with his/her child, and this method may help parents to learn more and enjoy the experience from other parents.

In brief, a mixed methods approach of quantitative and qualitative was designed for this research in order to generate a rather rich set of data and comprehensive picture of intervention and management strategies for anxiety. These methods were appropriated in the current research, as they appeared to be the most suitable method for achieving the research aims. These various methods of quantitative and qualitative techniques captured

both the more general and subjective aspects of the experience under investigation, and were accordingly appropriate for the research objectives.

The aim of this research was to explore the prevalence of anxiety in children and young people with LD and autism and to develop a parental programme of anxiety management strategies “Calm Child Programme”. The researcher first identified the prevalence of anxiety in children and young people by employing a quantitative method. This was followed by exploring and developing a programme of management strategies for parents to use in relation to their children’s and young people’s anxiety. Management strategies for anxiety in children and young people were identified through semi-structured interviews with parents, carers and teachers who had been purposefully identified based on their children’s / young people’s anxiety score. To gain expert opinion, the Delphi method was applied to obtain a consensus between professionals regarding the appropriate and most useful strategies for those children and young people. The Calm Child Programme was developed via Delphi method. Finally, the Calm Child programme implemented with parents of children and young people with LD and autism integrated both quantitative and qualitative approaches. Ideally, the findings of this research will contribute directly to our understanding of parental management strategies and how parents can support their children and young people managing the anxiety.

The current methodology of research addresses children and young people with LD and autism, identifying two key methodological issues:

- (1) Methodologies with children and young people with LD & autism, and
- (2) Research methodologies involving parents in interventions.

### **3.2.1. Methodologies with children and young people with learning disabilities and autism**

The following section presents the key methodologies in children and young people with LD and autism specifically affecting the current study; issues in relation to prevalence and intervention studies. Through reviewing previous research conducted with children and young people with LD and autism, it was possible to identify some of the methodological approaches for conducting research in the screening and intervention research.

#### *Methodologies for assessment of mental health problems in children and young people*

The assessment of anxiety in children and young people with LD and autism is challenging endeavours (Cooray and Bakala 2005; Sullivan et al. 2007; MacNeil et al. 2009), as discussed in the literature review chapter. Literature indicated that the majority of studies dominantly used parents' report measures (Sofronoff et al. 2005; Sofronoff et al. 2005; Kim et al. 2000; Weisbrot et al. 2005; Reaven & Hepburn 2003; Sofronoff & Attwood 2003; Lehmkuhl et al. 2008), or a combination of parents' assessment in addition to other assessments, such as a self report measurement (e.g. Gillott et al. 2001; Farrugia & Hudson 2006; Chalfant et al. 2007). Some studies used both parents' and teachers' report (e.g. Weisbrot et al. 2005), or used clinical interview and anxiety scales, for instance the Spence anxiety scale (e.g. Chalfant et al. 2007), and the James and the Maths Test (e.g. Sofronoff & Atwood 2003; Sofronoff et al. 2005).

The assessment of anxiety in children and young people with LD and autism is challenging. As a result a number of approaches have been suggested in the literature when assessing children with learning disabilities. Firstly, the assessment of anxiety should use of multiple informants and multimodal assessment techniques (e.g. anxiety rating scales, clinical interviews, direct observation and behaviourally anchored measures (Grodén et al. 2006;

Romanczyk & Gillis 2006; Tsai 2006; MacNeil et al. 2009). Secondly, the assessment relies on third party information from a person who knows the child very well, and direct observations of the child's behaviour and functioning in different setting (Raghavan and Patel 2005). These challenges were considered in the current research, as assessment of anxiety in children and young people relied on parents', carers' and teachers' report. Another key factor of assessing anxiety was to administer multiple assessment techniques to screen for anxiety, using two standardized rating scales.

### Intervention studies

Most research on anxiety treatment for children and young people with autism spectrum disorders focuses on children and adolescents with high functioning autism and Asperger's syndrome, aged between 7 and 13 years old, except one case study involving 23-year old adults (Cardaciotto and Harbert 2004).

The majority of intervention studies conducted with children and young people with either LD or autism spectrum disorders concerning mental health have consistently reported intervention programmes lasting between 6 and 14 weeks. These studies have shown improvement in children and young people with LD and ASD in the indicated periods. Therefore, the researcher found that interventions lasting for a maximum period of 13 weeks (three months) can be useful for children and young people with LD and autism (see literature review chapter for details).

### **3.2.2. Methodologies in involving parents in interventions**

A review of methodologies from several studies involving parents in interventions indicates that parental involvement has taken a wide range of formats. Examples include parent training and workshops and parents as co-therapists. Additionally, parents can be provided with training materials, e.g.

information back, video-tape (Matson et al. 2009) (see literature review chapter 2).

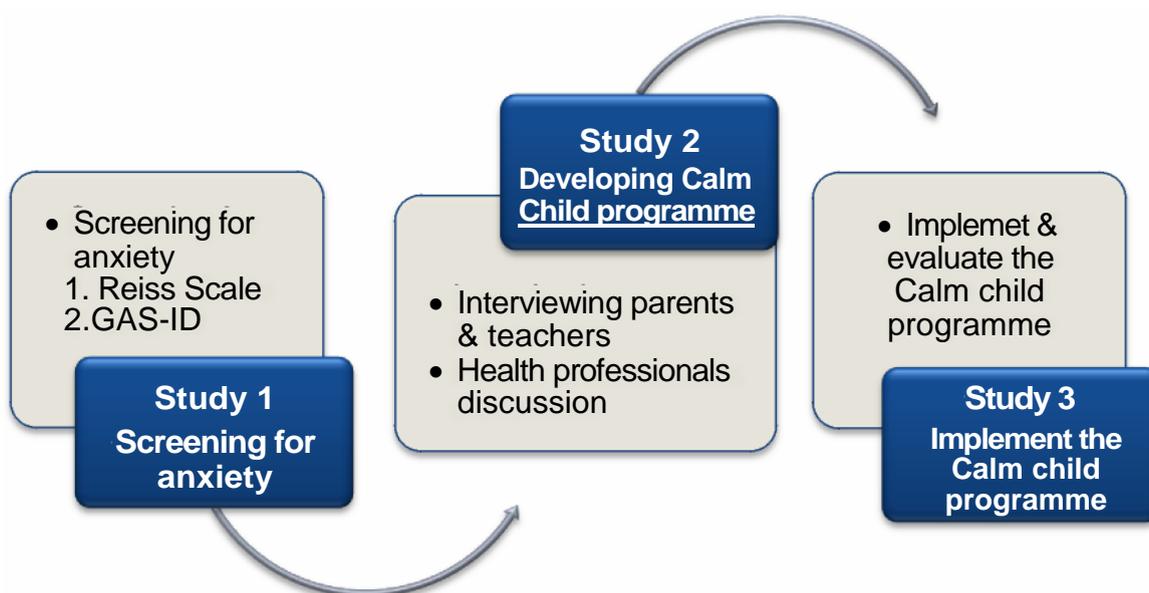
Research shows that interviews have been used as a research tool with parents of children with LD, and autism in several studies. This can be illustrated by Muris et al. (1998) who interviewed parents of children with autism using the diagnostic interview schedule for children to examine the prevalence of anxiety. Also, Emerson et al. (2004) conducted interviews with parents and teachers of children with LD to identify the emotional and behavioural needs of children and adolescents with LD; Bibby et al. (2002) interviewed parents regarding the anxiety intervention that their child had received. Reviews of the methodology of involving parents in the intervention indicated the use of both semi-structured (e.g. Itzchak et al. 2008) and structured interviews (e.g. Chalfant et al. 2007; Bellini 2004 a; Sofronoff and Attwood 2003; Mudford et al. 2001). In line with these methodologies, semi-structured interviews were used with parents in this research.

Although, there is growing research interest in the role of parents in supporting children with LD and autism (e.g. Sheinkopf & Siegel 1998; Hastings & Johnson 2001; Sofronoff and Attwood 2003; Green et al. 2006; Heiman and Berger 2008; Van der Bruggen, Stams, and Bogels 2008), less is known about management strategies introduced by parents at home. Further research is needed to focus on the parental interventions. This research aims to address the parental management strategies for children and young people with LD and autism. The purpose of this research was to develop and implement parental management strategies, to help their children and young people with autism to cope with anxiety. Undertaking this research methodology with parents of children and young people with LD and autism provided an opportunity to explore how parents can help their children and young people to manage these problems on a daily basis. In addition, this research represents an attempt to develop and implement more adequate coping strategies and to enable parents to better manage their children's and young people's anxiety.

### 3.3. STUDY DESIGN

This research consists of three interlinked studies. These are screening, developing a parental programme “Calm Child Programme”, and implementing Calm Child Programme study, as shown in Figure 3 (a). In study one, children and young people with LD and autism were screened for anxiety. In study two, children and young people who tested positive for anxiety, their parents, carers and teachers were then interviewed to explore the management strategies they used with their children and young people for anxiety. The information gathered from parents, carers and teachers was discussed with expert panel of health professionals to gain expert opinion in terms of anxiety management strategies and to develop a programme for use by parents. Finally, in study three, the developed programme of management strategies was implemented with a small sample of parents of children and young people with LD and autism.

**Figure 3 (a): The study design.**



### **3.4. DETAILS OF THE STUDIES**

The method involved in each study is outlined in this section.

#### **3.4.1. Screening study**

Period: September 2006- March. 2007

Screening was the first study of this research. This involved screening for mental health and anxiety in children and young people with LD and autism. The main purpose of conducting the screening was to identify the prevalence of anxiety in these children and young people with LD and autism. Then, to identify those parents of children and young people with LD and autism who tested positive for anxiety and invite them to participate in developing a Calm Child Programme study investigating management strategies for anxiety (study2).

150 children and young people with LD and autism were screened for mental health problems using the Reiss Scale. The Reiss Scale is organised into ten sub - scales for mental health problems, including one entitled anxiety (see chapter 4).

#### **3.4.2. Develop Calm Child programme of management strategies**

Period: Feb. 2007- Feb. 2008

The second study of this research was to develop a Calm Child Programme of management strategies for anxiety. This has two aims: 1) To identify everyday strategies that parents and teachers use to manage anxiety in children and young people with LD and autism and 2) To develop a parental programme of management strategies in managing anxiety for children and young people with LD and autism, incorporating the views of parents and health professionals.

### **Phase 1: “Exploration of anxiety management strategies”**

In order to identify effective anxiety management strategies, semi-structured interviews were conducted with parents, carers and teachers. Parents“, carer“s and teachers“ interviews aimed to explore management strategies for anxiety in everyday life for children & young people with LD and autism who have anxiety as per the screening study. It is more likely that some children and young people with LD and autism who have anxiety may have formal or informal management strategies for his / her anxiety and related behaviours provided by parents, teachers and carers.

### **Phase 2: “Developing a parental programme for anxiety management”**

In order to develop a parental programme of anxiety management strategies, the Delphi method was utilised. The aim of the Delphi technique was to discuss the strategies revealed by parents, carers and teachers with an expert panel of health professionals in order to obtain their agreement about what are appropriate and effective strategies for anxiety in children & young people with LD and autism. Subsequently, Calm Child Programme, a consensus of management strategies from both parents“ experience and health professionals“ views was developed, identifying practical and effective strategies for managing anxiety in children and young people with LD and autism.

#### **3.4.3. Implementing the Calm Child Programme**

Period: Mar.2008 –Sep. 2008

The last study of this research was implementing the Calm Child Programme of management strategies. The Calm Child Programme of parental management strategies was implemented with a small group of parents caring for children and young people with LD and autism for three months to evaluate its use.

### 3.5. PARTICIPANTS

The participants in this research include parents caring for children and young people with LD and autism disorders. This research was conducted in two different locations in the United Kingdom (West Yorkshire and the North East of England). The participants of the first and the second study of this research were recruited from a district in West Yorkshire, while the third study was conducted in two regions, the North East and West Yorkshire. Participants were selected from Special Education Schools and Autism Support Groups as well as the children and adolescents mental health services database.

The children and young people with LD and autism were selected according to the following inclusion criteria:

- Children and young people with mild to moderate learning disabilities (evidence through their statement and information from parents).
- Have a diagnosis of autism disorders, evidenced from their statement report at school, and from parents.
- Aged 5-18 years.
- Attending a Special Education School or a mainstream School.
- Living at home with their parents.

For a small number of children, a statutory assessment of their SEN (Special Education Needs) may be undertaken by the LA (Local Authority), whose staff will then consider whether or not to issue a statement of SEN (DfES 2001). According to Special Education Needs Codes of Practice (2001), a statement is a document that describes all the child's SEN and the special support that the child should receive (DfES 2001). The LA will usually make a statement if they decide that all the special help the child needs cannot be provided within the school's resources. These resources could include money, staff time and special equipment (DfCSF 2009; PP. 25). There is an

annual review of the statement at least once a year. LA's must check the child's progress and make sure that the statement continues to meet their special educational needs (DfCSF 2009).

The statement would provide additional support to help the child's progress. This may not show the actual function level of the child's LD or autism. Instead, it may inform the services of the type and kind of help the child needs. Within their SEN statements, all of the children and young people participating in the study had a diagnosis of LD and ASD made by a psychiatrist or a psychologist.

Overall, participants being involved in this research were for the screening: parents, carers and teachers of 150 children and young people; 119 males, 31 females. Children and young people were aged 5-18 years, with a mean age of 12.25 years (SD= 3.47). In terms of the second study (developing Calm Child programme) 34 parents, carers and teachers participated. In addition, parents of seven children and young people with LD and autism spectrum disorders from a metropolitan district living in West Yorkshire and North East of England were involved in the implementing study. The children and young people aged 5-14 years and had a mean age of 8.86 (SD = 2.79).

### **3.6. MEASURES AND INSTRUMENTS**

The instruments of data collection used in this research included the Reiss Scale for children's dual diagnosis and the Glasgow Anxiety Scale for Intellectual Disabilities (GAS-ID) for screening for anxiety. These were used in the first study of this research as the screening study. The full details of these scales are documented in chapter 4. The qualitative methods involved semi-structured interviews, Delphi technique, and focus groups. The interviews and Delphi technique were used in the second study of this research in developing a Calm Child Programme study (chapter 5). The

focus group was used in the third study of implementing Calm Child Programme, and details are presented in chapter 6.

### **3.7. DATA COLLECTION**

The first study of this research was a screening for anxiety. Two rating scales were used for the data collection. These are the Reiss Scale for children's dual diagnosis, and the Glasgow anxiety scale. In this study the Reiss Scale was completed by parents and teachers as first stage screening instruments. Children and young people with scores at or above the cut-off score were identified as potential cases and evaluated further. In the second stage, children and young people with scores at or above the cut-off score completed the Glasgow anxiety scale. The overall prevalence of anxiety was determined by the second score on the Glasgow scale. At the end of this study a number of children and young people were identified as anxious, and parents and teachers were invited for interview as the next study of this research.

The second study of this research was to develop a programme of parental management strategies for anxiety "Calm Child Programme". Data collection for the study was conducted using semi-structured interviews and the Delphi technique. The interview schedule was developed for parents, carers and teachers of children and young people with LD and autism, exploring the different ways of managing their children's and young people's anxiety at home and at school in day-to-day life. On the second stage of this study the Delphi technique was conducted with health professionals. The interview schedule can be found in Appendix - VIII, and professional information sheet in Appendix - IX.

The final study of this research was implementing the Calm Child Programme. Parents from the early sample, in addition to new parents, were invited to participate in the study. The interested participants were invited to

receive information on how the programme would be carried out and on the assessment criteria. Data collection for this study was conducted using GAS-ID pre and post programme, in addition to focus groups. The focus group schedule was developed for parents to find out the impact of using the programme for three months with their children and young people. The focus group schedule is provided in Appendix - X. Details of the data collection methods for each of these studies are explained in the subsequent chapters (4, 5 and 6).

### **3.8. ETHICAL CONSIDERATION**

Ethics within a research project is an ongoing process (Northway 2000). This produces a challenge to the researcher to ensure that s/he does not take over control of the process (Chappell 2001), and that power is held equally between the researcher and participants (Chapman et al. 2004).

#### *Ethical approval for research*

Ethical approval for the study was sought and successfully granted from the local Research Ethics Committee prior to the study with due consideration given to safety, anonymity, confidentiality and expected involvement of participants, (see Appendix - I). Ethical approval was also obtained from University of Northumbria, School of Health, Community, and Education Studies Research Ethics Sub-Committee, (see Appendix . II).

#### *Informed consent*

Informed consent is an ethical issue which concerns ensuring adequate communication of the focus of the research (DiCicco-Bloom and Crabtree 2006; PP. 319). The consent has to be ongoing throughout the research (Rodgers 1999). Consistently within the research process participants have the right to be informed about the natural sequences of research in which they are involved (Denzin and Lincoln 2000). Informed consent is based on

an individual's ability to choose by understanding the information given, appreciating the consequences of the situation and being able to form that decision rationally (Clegg 1999). Participants have the right to withdraw from the research at any time (DiCicco-Bloom and Crabtree 2006).

### *Privacy and Confidentiality*

Codes of ethics insist on safeguards to protect people's identities and those of the research location (Denzin and Lincoln 2000). A parent / carer should be assured that what is communicated in the research will remain confidential to the researcher (Knight et al. 2006).

The researcher took appropriate steps with regard to informed consent, privacy, access, confidentiality and anonymity. In light of the documented ethical considerations, at each stage of the research, and through the research, the participants were aware of the purpose of the research and also given assurances that they would be supported to deal with any uncomfortable issues which arose during the study.

Informed consent has been sought and obtained from parents or carers of each participant, by stating clearly and simply why the research is being done and providing detailed information about what their involvement would entail. Meanwhile, the researcher explained the purpose and procedures of her study in clear and easy-to-understand language for children with LD. This was upon request from the parents if they wanted to explain their involvement in this research to their children. The children / young people information sheet is provided in Appendix - VI, and parent invitation letter in Appendix - V. This was used for the screening and developing Calm Child Programme studies of this research. Participants were also informed that they could withdraw from the research at any time without giving any reason. Finally, if consent was given, the participant was asked to sign a written consent form before commencing the data collection. A copy of the consent form used is included in Appendix - VII. The details of obtaining consent in

the particular studies are documented in chapters four, five and six. Participants signed consent forms before data collection began.

Relating to individuals' right to privacy with respect to the processing of personal data, the privacy of the participants was respected and the confidential nature of the study was communicated to all participants, parents, carers and others involved in the research. All the participants were informed that the data from the study would only be used for the sole purpose of this research project. They were also informed that their identity will be protected and their name, address or other personal information would not be used for the purpose of the study. All participants were identified by a code and their real names were not used to identify them to ensure confidentiality of participants. The code consisted of a number and two initials of the participant's name. Moreover, the personal data were stored in a secure place in a locked cabinet at the university. The participants were voluntary and had the right to withdraw at any time, so that the individual was not coerced into participation.

### **3.9. ORGANISATION AND CODING THE DATA**

This includes gathering all the data collected and preparing it for the analysis process. All interviews were audio taped. All interviews were transcribed into hard copy, and saved on the computer as a word document. For the purpose of confidentiality all the interviews were coded by specific code, giving initials and numbers. The data were coded into themes by sentence and words according to parents', carers' and teachers' narratives, and then it was counted how many parents had used those types of strategies. Finally, the data was ready for the analysis.

### **3.10. DATA ANALYSIS**

The qualitative and quantitative assessments employed in this research were analysed. The data analysis can be divided into two groups: statistical analysis and qualitative analysis.

#### **3.10.1. Statistical analysis**

The Statistical Package for the Social Sciences (SPSS) for Windows 15.0 was employed for the statistical analyses. For the screening study, both the standardised scales of Reiss and Gas-ID, administered in the present research, were analysed according to the instructions in each assessment manual, providing scores for all the participants. Data was entered onto a personal computer.

Descriptive statistics and comparison of means were used to examine the effect of the intervention and management strategies on reducing anxiety of children and young people with LD and autism for the pilot study. The non-parametric Wilcoxon-signed-rank test was used to analyse the changes between the pre- and post-intervention data, to thus determine if there were any statistically significant differences in the sample group pre- and post- the intervention on the Glasgow anxiety scale.

#### **3.10.2. Qualitative analysis**

The interview transcripts were analysed according to qualitative methods using “Thematic Content Analysis” (Denzin & Lincoln 2000; Robson 2002; Braun and Clarke 2006). Thematic Content Analysis is a type of qualitative analysis (Denzin and Lincoln 2000) which is a procedure for studying the contents and themes of written or transcribed qualitative data, usually by reducing it to more structured or concise units of information (Scherl and Smithson 1987). Braun and Clarke (2006) have defined Thematic Content Analysis as “a method for identifying, analysing and reporting patterns

(themes) within data” (PP.79). Themes are identified as something important within the data in relation to the research question and represent some level of patterned response or meaning within the data (Braun and Clarke 2006).

Qualitative data analysis was used for analysing the interviews. Using the transcribed interviews with key informants as data, the analysis aimed to develop a framework for management strategies, describing parents“, carers “ and teachers“ management strategies for anxiety. The processing of preparing the qualitative data for analysis included coding, memoing, mapping and finally reporting the result. Initially, the content of interview transcripts was coded by classifying or categorizing the strategies that were used by parents, carers and teachers. The researcher grouped the data of the transcripts to distil meaning identifying themes. Three themes emerged: (1) Antecedent of anxiety, (2) Management strategies and (3) Aims of strategies.

Creating categories occurred next, producing more refined results. Patterns were identified, revealing similarities that endorsed the emerging categories. A total of 7 related categories (i.e. emotional, cognitive, behavioural...) were identified under these themes as noted above (for more detail see chapter 5, table 5.2). Memoing or notes were written to capture code meaning, or theoretical ideas that will be useful during analysis. Lastly, concept mapping used diagrams to explore relationships in the data graphically. Finally, the results of these analyses were reported (see chapter 5 for the details of data analysis).

### **3.11. CONCLUSION**

This chapter has outlined the methodologies employed for this research involving parents of children and young people with LD and autism. A mixed methodology approach was used in this research. Combinations of quantitative and qualitative method approaches were employed for this

research in order to address the aims of this research. This chapter also examined the ethical considerations of research with parents of children and young people with LD and autism. The upcoming three chapters will discuss in detail the methods and results of the three studies in sequence.

## ***CHAPTER 4: SCREENING FOR ANXIETY***

### **4.1. INTRODUCTION**

This chapter describes the method of conducting the screening study, discussing participant characteristics, data collection procedures and data analysis, and finally summarizing the results obtained. The aim of the study was to screen a large sample of children and young people with LD and autism, thus identifying children and young people who experience anxiety. The purpose of conducting the screening was to explore the prevalence of anxiety in children and young people with LD and autism and also to identify participants for developing a Calm Child Programme study.

### **4.2. METHOD**

#### **4.2.1. Recruitment of participants**

Participants were parents, carers and teachers of children and young people with LD and autism living in West Yorkshire in England. Parents were recruited from a variety of sources including contact with Special Education Schools, Autism Support Groups (this is part of Education in West Yorkshire), Child and Adolescent Mental Health services (CAMHs) and organisations working with and for parents of children and young people with autism spectrum disorders.

The participants for the screening study were recruited from the Special Schools and parent support groups in West Yorkshire, UK. There are around 450 children and young people with learning disabilities registered on a Special Education database in the study location (a district in West Yorkshire). Records from Special Schools indicated that there are about 166 children and young people who have a diagnosis of LD and autism.

Invitation letters were sent to parents of these children and young people through the schools. Parents of 83 children and young people from five Special schools volunteered to participate in this study. In addition to this, 67 parents were also recruited from four different parent support groups in the study District. No cross reference was made to database of schools and support groups because of confidentiality issue. Overall, 150 parents caring for children and young people with LD and autism volunteered to take part in this research.

Invitation letters were sent to parents through Special Education Schools, Social support groups and other service users as outlined above. Initially, appointments were made with Head Teachers and managers of the social support groups to brief them about the project and ask them to forward the letters and information sheets to parents and teachers. These organisations, in turn, agreed to distribute a "parent"s letter" with the information sheet of the study to the relevant parents. After distributing the parent"s invitations letters through schools and social support groups, a number of parents returned the reply forms. Parents, carers and teachers who showed interest to participate in this project were appointed to complete Reiss Scale. Consent was obtained from the parents to screen for anxiety for this research prior to completing the scale.

Consent was obtained through the following process: participants were provided with the research information. In addition, they were informed that all the information they provided would be treated as strictly confidential and used only for the purpose of this research. Participants were also informed that they could withdraw from the research at any time without giving any reason. Participants signed consent forms before data collection began.

#### **4.2.2. Participants**

Parents, carers and teachers of 150 children and young people with LD and autism aged 5-18 years (119 males, 31 females), with a mean age of

12.25 years (SD= 3.47) participated in the screening study. 75 (50%) were children aged 5-12 years (60 males, 15 females) with a mean age of 9.4 years. While the other 75 (50%) were young people aged 13-18 years (59 males, 16 females) with a mean age of 15 years, as shown in table 4.1.

**Table 4.1. Number of participants according to age groups and gender of the sample**

Group	Age range (years)	Mean age (year)	Male	Female	Total No.
Children	5-12	9.4	60	15	75
Young People	13-18	15	59	16	75
<b>Total</b>	5-18	12.25	119	31	150

#### 4.2.3. Measures and instruments

Two screening tools were used to screen for anxiety in this study.

##### 1) Reiss Scales for Children’s Dual Diagnosis (Reiss and Valenti-Hein 1990).

The Reiss Scales for Children’s Dual Diagnosis (Reiss Scale) is a screening tool for multiple mental health problems with people with LD. The Reiss scale contains 60 items (symptoms of psychopathology) based on the DSM-III-R classification of psychopathology (American Psychiatric Association 1987). Each item has five descriptive items, scored as 0 (No problem), 1 (Problem), or 2 (A major problem) by two people familiar with the participant, and the scores are averaged. The Reiss Scale manual suggests that the raters (e.g. parents, carers and teachers) should know the child well enough to make a valid rating of behaviour and emotion. The 60 items are organized into 10 psychometric subscales, derived through factor analysis, including one entitled Anxiety. Reiss & Valenti-Hein (1990) suggest that each item on the Reiss Scale is presented in three parts: the name of the symptoms (e.g. anxiety); a non-technical definition (e.g. appears nervous or tense); and

common behavioural examples (e.g. nervous, overreacts to unexpected sounds or events, vigilant, worried).

The scale was developed in the United States of America. Studies using this screening instrument were largely based on the USA population of people with learning disabilities (Reiss 1990; Reiss & Valenti-Hein 1994). It is considered to be a good screening instrument to identify psychological disturbance and particular problem behaviours in children with learning disabilities, who constitute the scales' normative group (Prout 1993). According to the authors (Reiss & Valenti-Hein 1994), the Reiss Scale is psychometrically sound, with excellent internal reliability, Cronbach's alpha of 0.91 to 0.92, good factor content validity, and factor loadings of 0.42 to 0.83.

The reasons of selecting the Reiss Scale for this research were based on the following:

- n It is a brief mental health screening tool that can be administered to parents and teachers of 4 to 21-year-old children with LD.
- n The relative merit of the Reiss Scale is based on its completion by parents, teachers, or whoever knows the child very well. In line with the literature it is recommended that parents are to rate the scale, as parents have been found to be a good source to identify anxiety in children with autism (Sukhodolsky et al. 2008) (see literature review chapter 2). Therefore, this Reiss Scale has been adopted in this research.
- n It is easy to be understood by carers (Reiss & Valenti-Hein 1990). According to Reiss, the purpose of the definitions and common behavioural examples is to improve the understanding of items on the part of the raters, who in the majority of cases are not mental health professionals, but unqualified carers.
- n It is brief, requiring approximately 15 minutes to complete. It is quite short, comprising of 60 items, compared with other scales (for example,

DASH-II consists of 84 items, and PAS-ADD is an 86 item scale).

Hence, parents do not feel exhausted by reaching the last questions.

- These mental health scales covered common areas of emotional and behavioural difficulties for children.
- Lastly, it has been indicated that it has excellent internal reliability and good factor content validity (Reiss & Valenti-Hein 1994).

Overall, the Reiss Scale provided the researcher with the most relevant and applicable criteria to this research participants, as rated by parents and teachers, and are easy and quick to use. Other alternative scales, for instance DASH-II, were found as inappropriate to this research, as this is designed for people with severe and profound LD, while this research focuses on children with mild to moderate LD.

### **Scoring of Reiss Scale**

The scoring system of the Reiss Scale is the sum of all the 60 items, consisting of the (1) ten scale scores and (2) the ten scores for the significant behaviour items. The ten scales score are: Anger, Anxiety, Attention-deficit, Autism/Pervasive, Conduct Disorder, Depression, Poor Self-Esteem, Psychosis, Somatoform Behaviour, and Withdrawn/Isolated. These subscales each have five items. Additionally, the Reiss scale measures 10 “other significant behaviours” including Crying spells, Enuresis / Hallucinations, Involuntary movements, Lies, Obese, Pica, Sets fires, Sexual problem, and Verbally abusive. These subscales each have one item.

In order to screen a child with learning disability for mental health problems, the 60 item total score is used as the overall score. In the 60 item total score, a child is considered to test positive for mental health if he/she scored 29 or above on that category. In the ten scale scores, a person is considered to test positive for each of these item if he/she scored 5/6 or above on each of

these categories according to the cut-off point for each scale. In the “other significant behaviour” items, a child is considered to test positive for these item if he/she scored 1.5 or above on each of the items. A list of the various items and their cut off scores are provided in Appendix (XI).

A 60 item total score is computed to identify whether a child has tested positive or negative for mental health problems using the cut off score. According to the Reiss Scale test manual, a child is considered to test “positive” for mental health problems if one or both of the following conditions are true:

1. The total score is 29 or higher.
2. At least two of the ten psychometric scales are at or above the suggested cut-off points.

A child is considered to test “negative” for mental health problems if both of the following are true:

1. The total score is 28 or less.
2. The number of psychometric scales with scores at or above the suggested cut-off point is one or none.

### **Interpretation of Test Results**

According to the Reiss Scale manual, a positive test result means that the subject is likely to need mental health services (Reiss & Valenti-Hein 1990). However, additional evaluations by qualified mental health professionals are needed to determine whether or not the subject in fact has a mental health problems and what services are needed. All of the children and young people had been seen by health professional. As a result, there were no issues to the referral to health professionals regarding those children and young people who scored positive for mental health problems or anxiety.

## **2) Glasgow Anxiety Scale for Intellectual Disability (GAS-ID)**

(Mindham and Espie 2003).

The Glasgow anxiety scale (GAS-ID) is a measurement for use with people with mild learning disabilities (Mindham & Espie 2003). It is a self-rating scale. The GAS-ID was developed in Great Britain, Glasgow University by Mindham & Espie (2003), and has been used by other researchers with participants with LD (e.g. Douglass, Palmer and O'Connor 2007; Dagnan & Jahoda 2008) in the English population. According to Mindham & Espie's study (2003) the GAS-ID has yielded some promising results in terms of psychometric properties and practical utility with people with mild learning disabilities. This scale has been used in this research with permission from the authors.

In this research, it was felt that the GAS-ID scale could be easily and appropriately used to this group. According to the GAS-ID scale, a child should be assisted by a person who is related to him/her; though in this research parents were asked to complete the scale on behalf of their children. There were two reasons for this. Firstly, it was a challenge to identify anxiety in those children with autism (Sullivan et al. 2007; MacNeil et al. 2009). This is due to communication difficulties that children with autism experience, being unable to address their emotional experience accurately, as discussed in the literature review chapter. Secondly, it was recommended to ask parents, or individuals who knew the child very well, to complete these scales (Raghavan and Patel 2005).

The rationale for choosing the GAS-ID was based on several reasons as discussed below:

- 1) It is suggested as a useful measure for both clinical practice and research.
- 2) It offers to be "user friendly" taking only 5 -10 minutes to administer (Mindham & Espie 2003).

3) According to the Authors (Mindham & Epsie 2003), it has been shown to have good reliability, and validity.

GAS-ID is a screening tool for anxiety, consisting of 27 items. Each item is scored on a 3 option scale from 0 to 2. The GAS-ID screen requires participants to rate their level of symptoms in terms of use. This is to say whether the symptoms currently “*Always*”, “*Sometimes*”, or “*Never*” appear in the last three months of the person being evaluated. These are concepts that they are familiar with and understood. Cue cards with visual representations of “*Never*”, “*Sometimes*”, and “*Always*” have been used to demonstrate the responses. The GAS-ID manual suggests that the interviewer asks the participant for each question whether s/he has “never felt this symptom”, “sometimes felt this symptom”, or “always felt this symptom”. The manual also suggests that the items should be read out to the participants (or he or she assisted to read them).

### **Scoring of GAS- ID**

The scoring system of the GAS-ID consists of: (1) three scale scores and (2) the 27 item total score. Scores on this measure could range from 0 to 54. Mindham & Espie (2003) tentatively suggest a cut-off score of 20 as a threshold value to identify possible anxiety. The three scale scores are worries, specific fears, and physiological symptoms. The first scale for the worries has 10 items, the second scale for specific fears has 9 items, and the third scale for the physiological symptoms has 8 items.

A 27- item total score is computed to identify whether a person had tested positive or negative for anxiety disorder using the cut off score. According to the GAS-ID test manual, a child with learning disability is considered to test “positive” for anxiety if the 27 item total score is at or above the cut-off points, if s/he scored 20 or above in this category.

### **4.3. DATA COLLECTION**

The aim of this study was to screen a large sample of children and young people with LD and autism, thus identifying children and young people who experience anxiety. This was done on two stage screening processes, the Reiss Scale and the Glasgow Anxiety Scale for Intellectual Disabilities (GAS-ID). The Reiss scale screening revealed children tested positive for mental health problems and some positive for anxiety, and then a second screening was carried out using GAS-ID. The rationale of conducting this screening study was to identify the prevalence rates of anxiety in those children and young people and also to obtain a sample of 50 parents of children with LD and autism who could be interviewed to explore the types of intervention strategies used for the management of anxiety of their children.

#### **4.3.1. Procedure for Reiss screening**

Parents who received the invitation letter and who were interested to participate were asked to contact the researcher at a secure e-mail address or to send the reply letter using the researcher self-addressed envelope. Interested participants were selected to complete the Reiss Scale. Consent was obtained prior to start, as discussed earlier in this chapter. They were also assured about confidentiality. The purpose of the study was explained and the parents and teachers were introduced to the Reiss Scale. The instructions in the Reiss Scale Manual (Reiss & Valenti-Hein 1990) were used to inform the raters (parents and teachers) about the methodology of rating the child for the study. The parents and the teachers had an opportunity to read the instructions and to ask any questions regarding the completion of the Reiss Scale.

The mental health problems and anxiety of 150 children with LD and autism disorders were assessed by parents' and teachers' reports using the Reiss Scale for mental health problems. This process identified 92 children and young people who tested positive for mental health problems. Of these, 54

children and young people tested positive for anxiety at or above the cut-off point on anxiety subscale for Reiss. Children and young people who tested positive for the anxiety subscale on Reiss Scale were asked to complete the Glasgow anxiety scale.

#### 4.3.2. Procedure for GAS-ID

Parents of the 54 children who tested positive for anxiety on Reiss Scale were contacted to arrange a meeting to complete GAS-ID anxiety scale to confirm the presence of anxiety. Participants were informed that all the information they provided would be treated as strictly confidential and used only for the purpose of the study. The instructions of Glasgow scale were explained to the parents and how they could rate the child's anxiety. Parents of forty nine children and young people completed GAS-ID scale in this study. Of these, 24 were children aged 5 -12 years, and 25 young people aged 13-18years, with a mean age of 12.3 (SD= 3.65). The majority of the children were males 85% (N= 42), while 14.3 % (N=7) were females.

**Table 4.2. Summary of numbers of participants for Reiss and GAS-ID according to the age and gender for Reiss and GAS-ID.**

Scale	Reiss (%)	Reiss (+ve MH)	Anxiety of Reiss (%)	Anxiety of GAS (%)
<b>Children</b>	75 (50%)	50 (33.3%)	29 (53.7%)	24 (49%)
<b>Young people</b>	75 (50%)	42 (28%)	25 (46.3%)	25 (51%)
<b>Male</b>	119 (79.4%)	74	47	42
<b>Female</b>	31 (20.6%)	18	7	7
<b>Total</b>	150	92 (61.3%)	54 (36%)	49 (32.6%)

MH= Mental Health, +ve = positive for mental health problems, GAS-ID = Glasgow Anxiety Scale for Intellectual Disability

#### 4. 4. DATA ANALYSIS

Descriptive statistics on SPSS were used for analysing the results. The prevalence of mental health problems and anxiety, mean and percentages were used to present the findings. Associations were investigated between anxiety, age and gender. The cut-off points provided in the Reiss manual - as indicated in Appendix (XI) - were used to identify children who scored at or above the cut-off score for further screening on GAS-ID. Frequency analysis was used for all children scored at or above GAS-ID cut-off point (=20). Correlations were investigated between anxiety, age and gender.

#### 4. 5. RESULTS

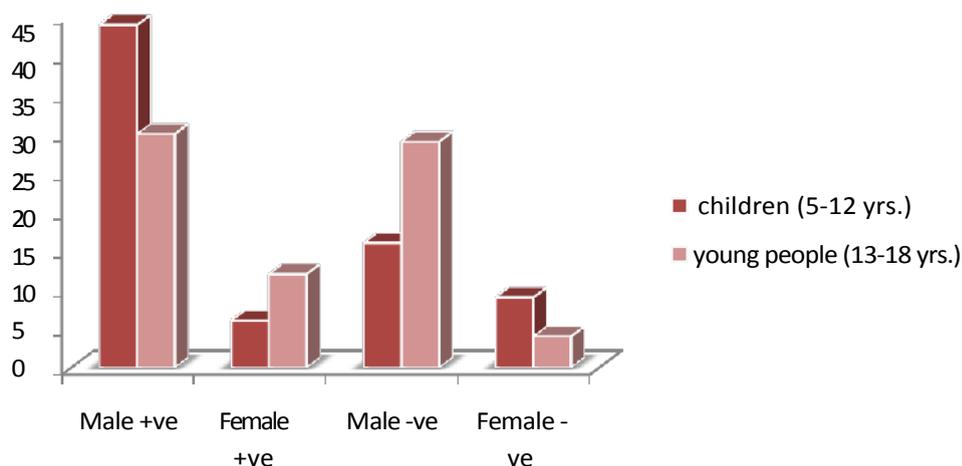
##### 4.5.1. Reiss screen

This study screened 150 children and young people with LD and autism for mental health problems, of which 119 (79.4%) were males and 31 (20.6%) females. Of the 150 children and young people, 61.3% (N=92) were identified as having mental health problems based on the total score criteria of the Reiss Scale. The remaining 38.7% (N = 58) tested negative for mental health problems using the total score criteria of the Reiss, as illustrated in table 4.3; figure 4 (b). Relative to the gender, a total of 74 males (44 children & 30 young people) and 18 females (6 children & 12 young people) tested positive for mental health problems.

**Table 4.3. Number of children and young people tested positive and negative for mental health problems using Reiss Scale.**

	Children (5-12 yrs)			young people (13-18 yrs)			Total		
	M	F	Total	M	F	Total	M	F	Total
<b>Positive (61.3%)</b>	44	6	50	30	12	42	74	18	92
<b>Negative (38%)</b>	16	9	25	29	4	33	45	13	58
<b>Total</b>	60	15	75	59	16	75	119	31	150

**Figure 4 (a): Number of children and young people tested positive and negative for mental health problems using Reiss Scale**

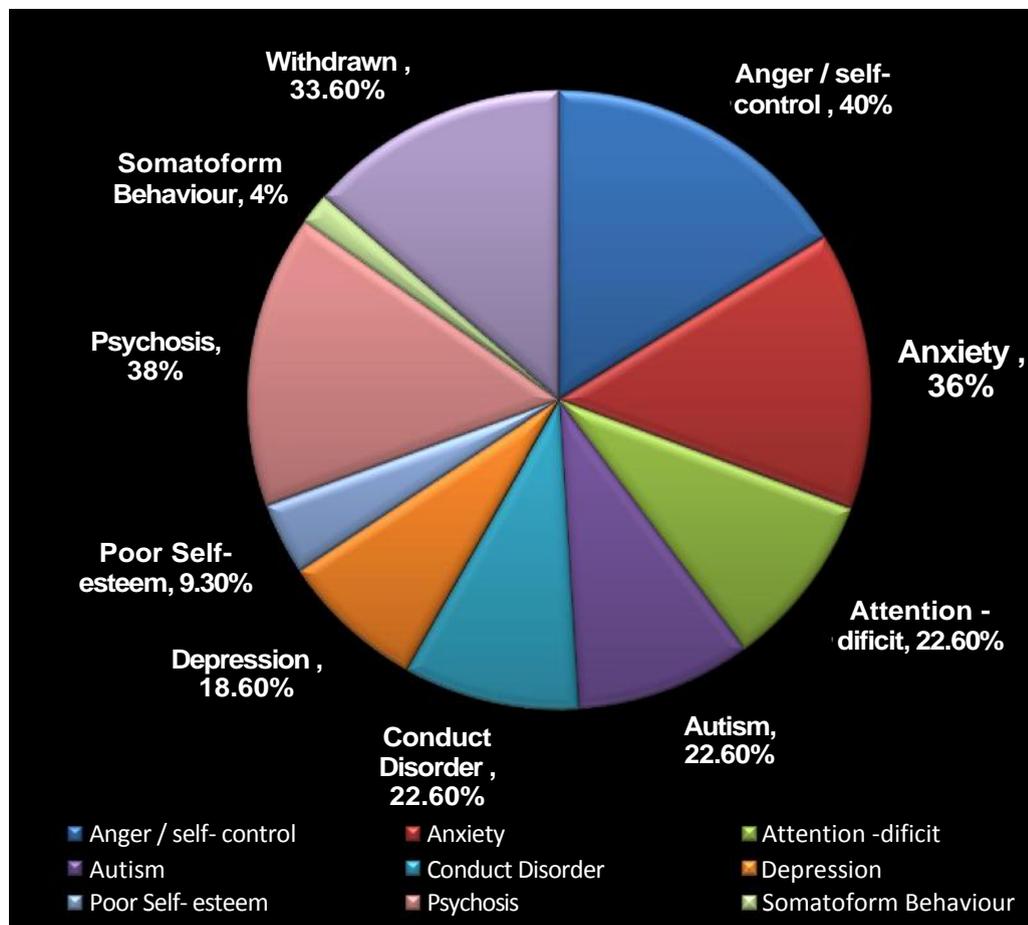


**Table 4.4. Number and percentage of individuals tested positive on each Reiss scoring criterion.**

Category	Male (%)	Female (%)	Total No.	Percentage
Anger	52 (3.5)	8 (.05)	60	40 %
Anxiety	47 (31.3)	7 (4.6)	54	36%
Attention deficit	28 (18.6)	6 (4)	34	22.6%
Autism	26 (17.3)	8 (5.3)	34	22.6%
Conduct disorder	28 (18.6)	6 (4)	34	22.6%
Depression	23 (15.3)	5 (3.3)	28	18.6%
Poor self esteem	13 (8.6)	1 (.6)	14	9.3%
Psychosis	47 (31.3)	11 (7.3)	58	38.6%
Somatoform behaviour	4 (2.6)	2 (1.3)	6	4%
Withdrawn	41 (27.3)	8 (5.3)	49	33.6%
Total Reiss (severity)	74 (49.3)	18 (12)	92	61.3%
TOTAL (N)	131	19	150	

Based on the above results (table 4.4), the findings of the Reiss screening indicated that 92 out of 150 (61.3%) tested positive for mental health problems. The highest aggregate scores among the 150 children and young people were in anger (40%), psychosis (38.6%), and for anxiety (36%). The withdrawn scale was 33.6%, while autism, attention deficit and conduct disorders had similar rates of 22.6%. Depression was 18%; poor self esteem was 9% and the lowest rate was for somatoform behaviour, being 4%, as shown in Figure 4 (b).

**Figure 4 (b): Percentage of individuals tested positive on each scoring criteria for Reiss Scale**

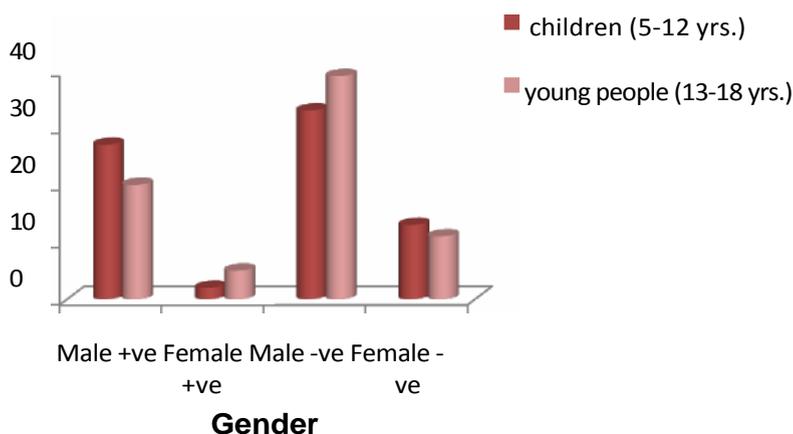


As this study was concerning the anxiety, the following section will focus on the scope of the anxiety. The results of the Reiss Scale indicated that 54 children and young people (36%) tested positive for anxiety, with a mean age of 11.85 (SD= 3.75). This counted for 47 males and 7 females; from which were 29 children (19.3%) and 25 were young people (16.7%), as shown in table 4.5 and Figure 4 (c) & 4 (d). It was noted that approximately two thirds of the sample (68.6%) at a particular age, ranged between 9 and 15 years. Moreover, results revealed that 66.6% of these children and young people in this age (9-15 years) tested positive for anxiety.

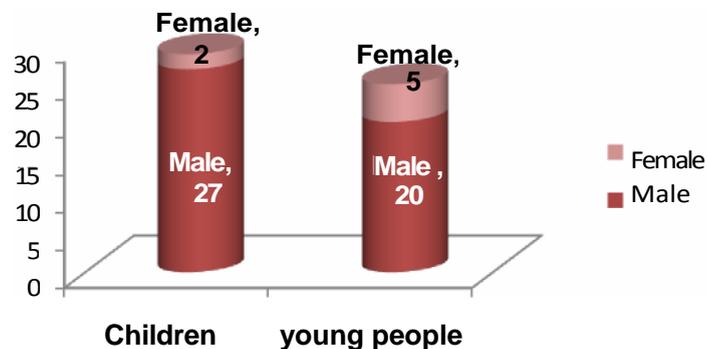
**Table 4.5. Age groups (children / young people) and gender tested positive and negative for anxiety subscale on Reiss Scale.**

Age	Children (5-12 yrs.)			Young people (13-18 yrs.)			Total	
	Gender	M	F	Total	M	F		Total
Positive anxiety		27	2	29	20	5	25	54
Negative anxiety		33	13	46	39	11	50	96
Rates of anxiety		38.6% (29 of 75)			33.3% (25 of 75)			36%

**Figure 4 (c): Age group and gender scored positive and negative for anxiety on Reiss subscale**



**Figure 4 (d): Age groups (children / young people) and gender tested positive for anxiety on Reiss subscale.**



**• Association between anxiety sub-score and mental health on Reiss**

Cross-tabulation (Chi-square test) was used to determine whether there was any association between the anxiety and mental health overall score on the Reiss Scale and the anxiety subscale on Reiss. The Chi-square test indicated that among children and young people with autism, 92.6% had mental health problems according to the Reiss Scale. However, up to one third (33.3%) of the overall sample had both mental health problems and anxiety on the Reiss Scale (table 4.6).

**Table 4.6. Reiss (positive (+ve) MH & negative (-ve) MH problems) anxiety (-ve anxiety & +ve anxiety) Cross-tabulation.**

Reiss		Anxiety		Total
		-ve anxiety	+ve anxiety	
<b>-ve MH problem</b>	No	54	4	58
	% within anxiety	56.3%	7.4%	38.7%
	% of Total	36.0%	2.7%	38.7%
<b>+ve MH problem</b>	Count	42	50	92
	% within anxiety	43.8%	<b>92.6%</b>	61.3%
	% of Total	28.0%	33.3%	61.3%
<b>Total</b>	No	96	54	150



## Anxiety and other mental health problems on Reiss Scale

It is suggested that children and young people who have anxiety may have other mental health problems on the Reiss Scale. From table 4.7 it can be inferred that the percentages of different mental health problems were varied, the highest percentages were for anger as well as psychosis (57.4%). The other high rate was for withdrawn 55.5%. The lowest percentage was for somatoform behaviour 9%.

**Table 4.7. Numbers and percentage of children and young people tested positive for anxiety and have other mental health problems.**

<b>5 I-LVVIFItI-JRrLI-VTRI Mental health problems</b>	<b>No of participants have other problems</b>	<b>Percentage %</b>
Anger	31	57.4%
Attention deficit	17	31.4%
Autism	24	44.4%
Conduct disorder	21	38%
Depression	20	37%
Poor self esteem	11	25.5%
Psychosis	31	57.4%
Somatoform behaviour	5	9.2%
Withdrawn	30	55.5%
Total Reiss (severity)	50	92.6%

### ***Anxiety subscale for Reiss***

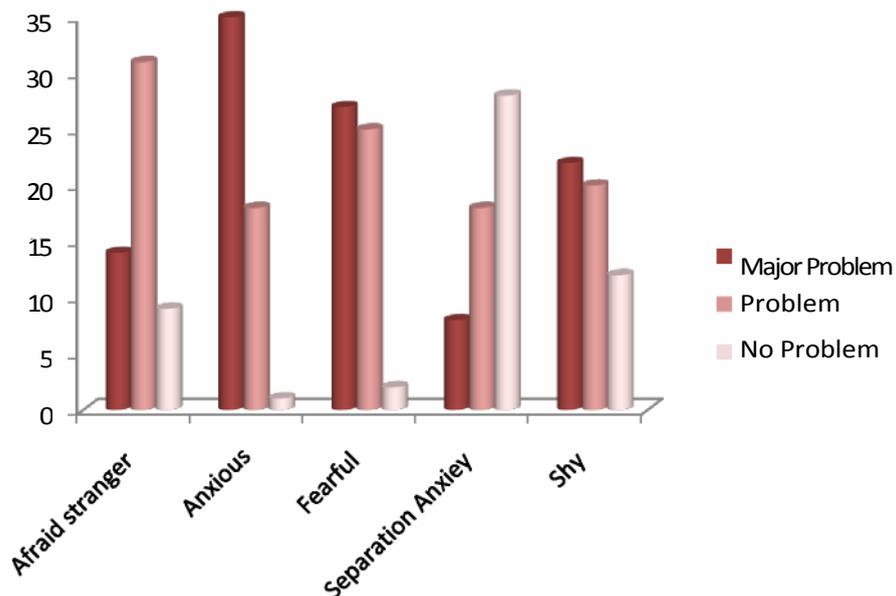
The component for the anxiety subscale represented five items including: being afraid of strangers, anxious, fearful, separation anxiety and shy. The indications were therefore showing that the vast majority of children were scored of major problem as anxious (N= 35), followed by fearful (N= 27),

then shy (N= 22) and being afraid of strangers (N= 14) while the minority was for separation anxiety (N=8) as can be seen in table 4.8 & figure 4 (e).

**Table 4.8. Prevalence of anxiety subscale for Reiss Scale**

Prevalence	Major problem	Problem	No problem
Afraid of strangers	14	31	9
Anxious	35	18	1
Fearful	27	25	2
Separation anxiety	8	18	28
Shy	22	20	12

**Figure 4 (e): Prevalence of anxiety subscale for Reiss Scale**



#### 4.5.2. GAS-ID Screen

Following the Reiss screening, all participants scored positive for anxiety on Reiss and were involved in the second screening phase using the Glasgow anxiety scale (GAS-ID). Forty nine out of fifty four (90.7%) children and young people who tested positive for anxiety on the Reiss Scale tested positive for anxiety on the GAS-ID scale, while the remaining five participants failed to complete the GAS-ID because of their autism and disability, or the scale was not applicable to them.

#### Agreement between anxiety scores in Reiss and GAS-ID

The findings revealed that all the 49 (100%) children and young people who completed the GAS-ID were tested positive for anxiety. These children and young people were also tested positive for anxiety on the Reiss anxiety subscale. Given this, it can be concluded that there was a strong agreement between anxiety scores on the Reiss and Glasgow anxiety scale, as shown in table 4.9 and 4.10.

**Table 4.9. Case Processing Summary for Reiss anxiety and GAS-ID**

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
<b>Reiss anxiety * GAS-ID</b>	49	90.7%	5	9.3%	54	100.0%

**Table 4.10. Reiss anxiety \* GAS-ID Cross tabulation**

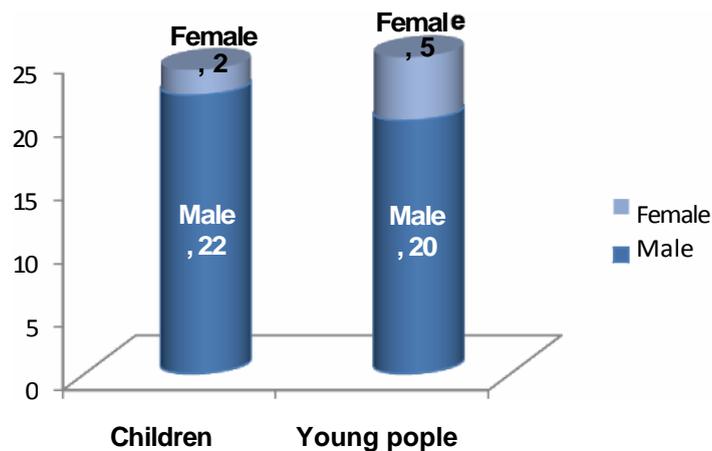
	GAS-ID		Total
Reiss anxiety	Anxiety	49	49
	Total	49	49

Table 4.11 shows that the mean age of the forty-nine children and young people tested positive for anxiety on the GAS (5-18 years) was 12.27 (SD= 3.62), of which 42 were males and 7 were females. Twenty four were children (5-18 years) and twenty five were young people (13-18 years), as shown in Figure 4 (f). These findings illustrated clearly that the number of children and young people who tested positive for anxiety on the GAS-ID were evenly distributed (24 children: 25 young people), as shown in figure 4 (g). However the percentage varied between genders (male 86 %, female 14%), as shown in Figure 4 (h). Therefore, it is suggested that the prevalence of anxiety is similar for children and young people

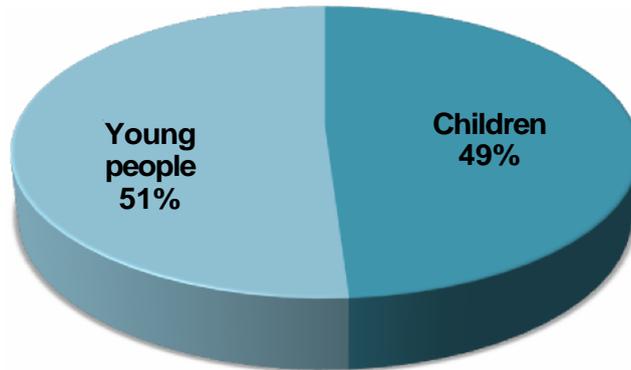
**Table 4.11. Frequency of age groups (children / young people) and gender tested positive for anxiety on GAS-ID scale.**

Age group	Children (5-12 yrs)	Young people (13-18 yrs)	Total (%)
Male	22	20	42
Female	2	5	7
Total	24 (49%)	25 (51%)	49 (32.6%)

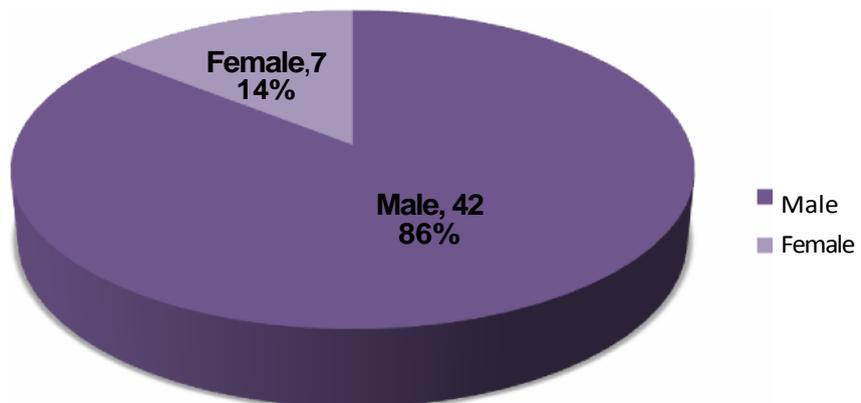
**Figure 4 (f): Age groups (children / young people) and gender tested positive for anxiety on GAS-ID scale**



**Figure 4 (g): Age groups (children / young people) tested positive for anxiety on GAS-ID scale**



**Figure 4 (h): Gender group (male / female) tested positive for anxiety on GAS-ID**



### Correlation between age and anxiety

To illustrate the differences of anxiety of total GAS-ID, and the GAS-ID subscales (worries, fears and physiological symptoms) on age, the age group variables were examined using Pearson correlation at level 0.05. The results indicated that there was no significant correlation between age and anxiety. This concurs with the previous frequency results which indicated that both age groups were evenly distributed for the prevalence of anxiety (table 4.9). However, the correlation was significant at 0.05 between the worries subscale and age ( $r = .337$ ,  $p = .018$ ), with growing up being associated with a higher worries rating. Meanwhile there was no correlation between age and both GAS-ID subscales of fears and physical symptoms, as shown on Table 4.12.

**Table: 4.12. Correlation between age, GAS, and GAS subscales (worries, fears and physiological symptoms)**

	<b>GAS</b>	<b>Worries</b>	<b>Fears</b>	<b>Physical</b>
<b>Age (r)</b>	.347	<b>.337*</b>	-.147	.103
(p)	.137	.018	0.312	0.481

\* Correlation is significant at the 0.05 level (2-tailed).

Table 4.13 provides descriptive details of the sample completing the GAS-ID (means and standard deviations). It can be indicated that overall the GAS-ID mean anxiety score was 28.2 (SD= 5.5), the mean for the worries subscale was 11.7 (SD= 2.9), mean of specific fears was 8.6 (SD = 2.8), and the mean for physiological symptoms was 7.8 (SD= 3.1). The results showed that the mean score of anxiety for males (M=28.6, SD= 5.5) was slightly higher than females (M= 25.6, SD=4.5).

**Table 4.13. Means and standard deviation for GAS-ID anxiety scale across anxiety subscales and gender and age.**

The results obtained indicated that the mean of the GAS-ID anxiety for

	LD & autism total group		Gender				Age (year)			
			Male		Female		5-12		13-18	
	M	S.D.	M	S.D.	M	S.D.	M	S.D.	M	S.D.
GAS anxiety	28.2	5.5	28.6	5.5	25.6	4.5	28.3	6.0	28.1	5.0
Worries	11.7	2.9	11.6	2.8	12.0	3.2	11.3	2.7	12.2	2.9
Fears	8.6	2.8	8.7	2.9	7.4	2.1	8.7	2.9	8.4	2.7
Physiological symptoms	7.8	3.1	8.1	3.1	6.1	3.1	8.0	3.4	7.6	2.8

children (M= 28.3) and young people (M= 28.1) were roughly similar, as illustrated in table 4.13. This was consistent again with above results of frequencies of children and young people as well as person correlation, indicating that there is no correlation between age and anxiety (table 4.12). This emphasises that the sample of children and of young people all had similar levels of anxiety.

According to the GAS-ID, anxiety manifests across a number of dimensions, including physiological, emotional, and cognitive components. GAS-ID illustrated the symptoms of each type. In terms of cognitive symptoms, worries involved lots of thoughts, worries about parents & family, doing something new, and worries about the future. Emotional symptoms involved some specific fears, for instance: being scared of the dark, heights, lifts or escalators, dogs, spiders, going to see the doctors or dentist, meeting new people and busy places. In addition, it illustrated some physiological symptoms, for example, feel very hot or sweaty, stomach feeling funny, hands and legs shaking, heart beats faster, breathlessness, feel panicky, find difficult to sit still and need to go to the toilet more than usual.

The results of the GAS-ID indicated that males and females seem to share a lot of similar fears and worries. They were worried a lot about doing something new, about parents and family. Furthermore the most prevalent specific fears are social phobia (fears of meeting new people and being in busy places), and fears of lifts or escalators, the dark and dogs. In terms of physiological symptoms feel panicky, feel very hot or sweaty, stomach feel funny and hands & legs shake were the most common symptoms.

#### **4.6. CONCLUSION**

The focus of this study was to screen for mental health problems and anxiety in children and young people with learning disabilities and autism. Two rating scales were used in this study. These were the Reiss Scale and the Glasgow Anxiety Scale. The results of this study revealed that the prevalence of mental health problems on children and young people aged 5 -18 years was 61.3%. The prevalence for anxiety on children and young people with LD and autism was 36% on Reiss and 32.6% on GAS-ID. Results indicated that 66.6% of those children who tested positive for anxiety on Reiss were aged 9 to 15 years. There were no significant differences according to age. In addition, there was no significant statistical correlation between age and GAS-ID anxiety. There was, however, a significant positive correlation at 0.05 between worries (GAS - ID subscale) and age ( $r = .337$ ,  $p = .018$ ). The findings indicated that the anxiety scores on the Reiss Scale were consistent with anxiety scores on the GAS-ID. The following chapter will focus on the development of a Calm Child Programme of anxiety management strategies.

# ***CHAPTER 5: DEVELOPING CALM CHILD PROGRAMME***

## **5.1. INTRODUCTION**

This chapter describes the methods of the second study of this research developing the Calm Child Programme (CCP) of anxiety management strategies using Delphi method. The participant characteristics, methods, data collection, the research procedures, the data analysis and the results are discussed.

### ***Aim***

The aim of this study was to develop a parental programme of management strategies. There are two phases in this study:

- (1) Exploration of anxiety management strategies used by parents and teachers.
- (2) Developing a parental programme for anxiety management strategies.

## **5.2. PHASE 1: EXPLORATION OF ANXIETY MANAGEMENT STRATEGIES USED BY PARENTS AND TEACHERS**

### **5.2.1. Method**

This study aimed to explore the strategies that parents and teachers used to manage anxiety in children and young people with LD and autism. A semi-structured interview schedule was developed to explore these management strategies used by parents and teachers. This included day-to-day activities and how these management strategies were used to manage the children's anxiety.

### **5.2.2. Recruitment of the participants**

Forty-nine children and young people from the screening study who tested positive for anxiety on both the Reiss anxiety subscale and Glasgow Anxiety Scale (GAS-ID) were recruited for this study. Thus, parents, carers and teachers of these children were invited to share their experiences of dealing with their children's anxiety. Letters of information were sent to prospective participants (parents and teachers). Participants were asked to contact the researcher by replying either through secure email, telephone or post. Thirty four parents, carers and teachers expressed an interest to take part in this study. The participants who expressed their wish to take part in this research project were contacted by telephone, and an interview time was scheduled accordingly. Interviews were arranged at a convenient time and location for the participants. These interviews were held at various sites; some were conducted in the homes of the participants, other interviews were conducted in the schools of the children or the social groups.

### **5.2.3. Participants**

Thirty four participants were interviewed which included twelve parents, two carers and twenty teachers. All were caring for children and young people with LD and autism with anxiety, as identified from the screening study (Table 5.1). Carers in this research were identified as individuals who were caring for a child; for example one grandparent and one foster parent. Some parents were caring for two children; also teachers were caring for more than one child. Overall, parents, carers and teachers were caring for 38 individuals (21 children and 17 young people; 33 males and 5 females). Children and young people ranged in age from 5 – 18 years. Some of the participants (parents and teachers) cared for the same child and the others a mixture. Few parents and teachers (N=4) were interviewed for the same child. Due to confidentiality issues, teachers used the initials or only letters of the children's names on the scale. This prevented to identify the scale completed by parents and teachers for the same child.

Informed consent was obtained from each participant prior to the interview. Before commencing the interview, the interviewer informed the participants of the aims and objectives of the research and explained the study protocol. All participants were informed of the procedures in place to preserve their confidentiality. They were informed of their right to withdraw from the research at any time and that withdrawal from the study would not affect their legal rights. The prospective participants were also informed that the interviews would be recorded using an audio-tape. All the participants were informed that the audio-tape recordings would only be used for the purpose of the transcripts for this study and would be destroyed after the transcription. A copy of the consent form used is included in Appendix - VII.

**Table 5.1. Numbers and percentage of participants**

<b>Group</b>	<b>Number</b>	<b>Percentage</b>
Parents	12	35%
Carers	2	6%
Teachers	20	59%
Children (5-12 yrs)	21	55%
Young People (13-18 yrs)	17	45%
Male	33	87%
Female	5	13%
<b>Total</b>	<b>34</b>	
<b>Parents &amp; teachers</b>	<b>38*</b>	
<b>Children &amp; young</b>		

\* The number of children were larger than number of parents and teachers, because some parents had two children, or teacher had more than one child.

#### **5.2.4. Measures and instruments**

Data collection for this study was conducted using semi-structured interviews. The focus of the interview was to explore the different strategies that parents, carers and teachers use to deal with their child's anxiety. Semi-structured interviews have predetermined questions, but the order can be modified based upon the interviewer's perception of what seems most

appropriate (Robson 2002). Semi-structured interview is a clear list of issues to be addressed and questions to be answered. The answers are open-ended, and there is more emphasis on the interviewee elaborating points of interest (Denscombe 2003).

The interview schedule was developed according to the following two-stage procedure:

### **1) Developing the questions of the interview schedule**

The researcher constructed the schedule based on her literature review of the interview method, studies focusing on anxiety among individuals with learning disabilities and autism, and general theories of anxiety. Based on this review, the researcher chose to construct the interview guide using open-ended questions that would allow participants the opportunity to express themselves freely without imposing too much structure (McCracken 1988).

There were three main themes for the main body of the interview. The first theme was to explore the anxiety (worries and fears) in children and young people. This included questions that provided information about the child's and young people's fears and worries. It was found that it was good to talk about the child's anxiety and whether it caused any problems for the child & young people and the parents: *"What are the types of worries / fears?"* *"Do you think these worries / fears are a problem for him / her and you?"*. The following question related to any kind of help parents, carers and teachers might have received. Then, whether it was difficult to keep the child relaxed / calm?

Second theme was to explore parents, carers and teachers experience of managing this anxiety. The main questions of the interview body were to delve into parents' insights of dealing with the child's anxiety: *"I'm interested in your experiences of management anxiety of your son / daughter. Can you give*

*me*

*an example of actions (steps) or things you have used to deal with your child's anxiety / fears? And how many times do you use these strategies with your son / daughter? Have you tried any other approaches / methods that you found useful?"*

The third theme focused on the effectiveness of these strategies. As the main body might have covered the parents', carers' and teachers' experience of dealing with the problem, it was also useful to identify its effectiveness. Then the following questions were developed: *Can you list the changes you have seen in your son / daughter since using management strategies for anxiety?; Can you describe how he / she felt when you started these approaches?; Do you think these approaches are actually working?; Do you try many anxiety management techniques? Can you determine what helps most?*

The interview schedule included an introduction and conclusion. In terms of developing the introduction, to begin with a friendly atmosphere with the participants, the researcher introduced herself with a brief introduction about the study and the aim of that interview, followed by assurance about the confidentiality. At the conclusion of the interview, participants were thanked and asked if they would like to add any aspects not covered in the interview: *"Can I finally ask you if you think there is any aspect of your experience of looking for treating / managing anxiety that has not been covered in this interview?"*.

Given this, the aspects of management strategies with their children's anxiety were discussed, including dealing with the children's fears and worries, and its effectiveness. In this proposal, the time estimated for interviews ran between 30 and 60 minutes.

## **2) Structure the interview schedule**

The researcher followed the interview guide when the interview schedule was developed, as based on Robson's (2002: PP. 277) guidance on the sequencing of questions as follows:

- I. *Introduction*: Interviewer introduces herself, explains the purpose of the interview, assures participants of confidentiality, and asks permission to tape record the interview.
- II. *Warm-up*: Easy questions are used at the beginning to build up a friendly atmosphere by asking a few questions about their son / daughter's anxiety.
- III. *Main body of the interview*: questions cover the main purpose of the interview, for example "*What are the types of your worried/ fears?*" "*Do you think these worries / fears are a problem for him / her and you?*". Then the interview covered the main questions regarding the management strategies "*I'm interested in your experiences of management anxiety of your son/ daughter, can you give me a specific example...?*".
- IV. *Cool off*: Usually a few straightforward questions at the end to defuse any tension that might have built up.
- V. *Closure*: Thank you and good bye.

This guide provided a general outline for the questions to be asked and served to talk about the topics under investigation. There are some elements which were considered when developing the interviews: The questions were put in a straightforward, clear and non-threatening way to avoid any confusion or create a defensive approach in the interviewee; and interviewer should not seek the correct answer by eliminating cues which lead interviewees to respond in a particular way (Robson 2002; PP. 274). The semi-structured interview-schedule is presented in Appendix - VIII.

### **Piloting the interview schedule**

Following the interview schedule design, this was piloted with two participants. Firstly, the participants were informed about the research, then there was a "small talk" warm up to establish a friendly atmosphere with the participants, until both parties were relatively comfortable, and assured about confidentiality. Then, participants were asked for their consent to tape record the interview. Next, the data from the interviews were entered into the

appropriate section of the interview schedule. Regarding the time constraint, it was expected to be finished within 30 minutes, while the interview might take 10-15 minutes longer depending on the parents' experience and the examples given.

Based on the piloted interview, when the participants were asked a follow up question "*is there any other aspect they would like to add*", one parent talked about some other strategies that she used with her son/daughter when s/he was younger (child). Accordingly, the researcher determined that a couple of questions should be added, these were:

- a) Did you use different techniques when s/he was small?
- b) Do you think those methods used when s/he was a child do not work now they have grown up?

These questions were only used with participants who have young people. In addition, some clarifying questions such as "*what do you mean by...?*" and "*Please tell me more about...*", as well as "*Can you give me a specific example of...?*" were included. This helped to modify the developed interview schedule.

#### **5.2.5. Data Collection**

Parents, carers and teachers were interviewed about management strategies they used for anxiety in children.

***Process of the interview:*** the interview process went as follows with individual participants:

The initial introduction was followed by a small talk and warm up to establish a friendly atmosphere with the participant, until both parties were relatively comfortable. The researcher introduced herself with a brief introduction about

the study and the aim of that interview, followed by assurance about the confidentiality. The researcher outlined the confidential nature of the interview and its time constraint as noted above, followed by gaining permission to tape record the interview. The participant then read and signed the ethical consent form. The interviews were recorded on a digital recorder in order to take advantage of higher quality recording. The audio recordings were sequentially initialled and numbered with the participant's code (i.e. 1JS). The participant then read and signed the ethical consent form. The participant was informed that they could stop the researcher at any time to clarify any questions. The interview began with the reading of the study's central or orienting question "*I'm interested in your experiences of management for anxiety*". As the participant proceeded to describe his / her experience, clarifying questions such as "*What do you mean by...?*" and "*Please tell me more about...* "; as well as "*Can you give me a specific example of...?*" were used as deemed appropriate. This practice was intended to remind the participant of the central question if she/he got too far off topic or forgot what the topic was, and helped to keep the focus of the interview on the central topic of the study as well as flesh out answers and passing remarks. After the open-ended segment of the interview, the participants were asked a follow-up question, "*Is there any other aspect that has not been covered in this interview?*", to help insure no relevant information was overlooked or forgotten. Lastly, at the end of the interview participants were thanked for participating in this research. The interview comprised of 12 questions, lasting between 30 - 45 minutes. The semi-structured interview-schedule is presented in Appendix - VIII.

#### **5.2.6. Data Analysis**

"Thematic Content Analysis" was conducted on the interview data. The interview transcript data presented a variety of themes associated with anxiety. Qualitative analysis of data involved identifications of themes and concepts related to anxiety that were organized into themes, and categories.

The three thematic concepts or factors emerged from the analysis included:

(1) Antecedent of anxiety, (2) Management strategies and (3) Aims of strategies. A total of 7 related categories were identified under these themes (table 5.2). Each of the three themes will be presented separately along with supporting data and schematic diagrams.

**Table 5.2 Thematic concepts: Qualitative dimensions of anxiety management strategies among children and young people with LD and autism.**

<p><b>Theme 1</b> Categories</p>	<p><b>Antecedents of Anxiety</b> Change in daily routine, meeting new people, new situation, noise, baby’s cries, dogs and cats, dentist, busy places, darkness, worries about family and futures.</p>
<p><b>Theme 2</b> Categories</p>	<p><b>Management strategies</b>   <i>Emotional:</i> Reassurance and Cuddling  <i>Cognitive:</i> Talking&amp; explaining, stop thinking, visual schedule (time-table), and grading anxiety.  <i>Behavioural:</i> Relaxation technique, physical activities, quiet time, distraction, have a little fun, rewarding, and flooding.  <i>Others:</i> Remove physically from situation and massage.</p>
<p><b>Theme 3</b> Categories</p>	<p><b>Aims of Strategies</b>   <i>Prevention:</i> Talking &amp; explaining, building up time table, physical activities.  <i>Reactive:</i> Quiet-out, distraction, Relaxation, have a little fun, rewarding, massage, Remove physically from situation and flooding.</p>

**Theme 1: Antecedents of anxiety**

Participants were asked to discuss the trigger factors of their child’s anxiety. Participants indicated several contributing events to the onset of anxiety, as shown in Figure 5 (a). These included a change in routine, for example holidays or a school trip. In the following excerpt, parents described how changes in routine, meeting new people, noise and other factors can lead to feelings of anxiety.

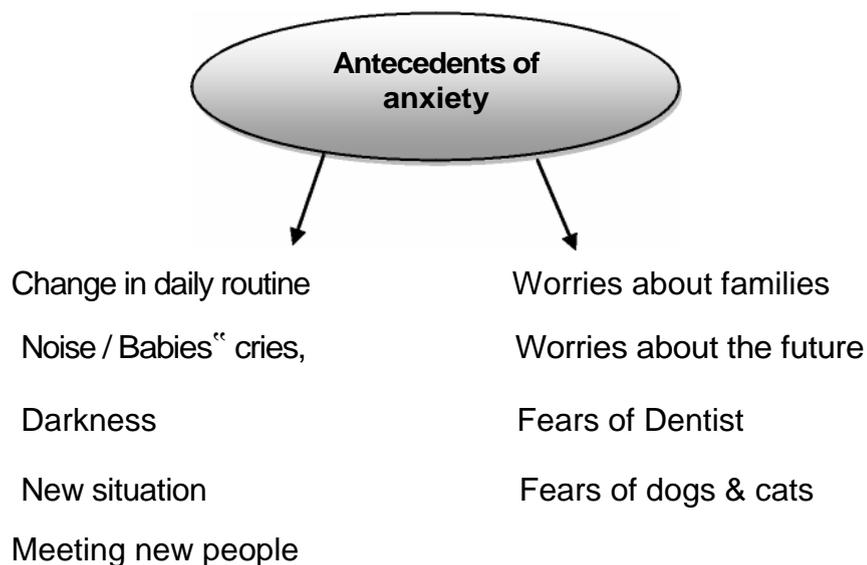
**Parent:** "Holiday is a major problem; she gets very very anxious going on holiday."

**Parent:** "He gets very very panicked about changing [routine], going out for a holiday, changing around new food; he likes to do the same things. He has a routine in the morning, so anything just out of his normal routine gets him anxious".

**Parent:** "He fears noise, especially crying small children, [he] tries to run away from small child"s cries. If we are in a supermarket and he finds a small child crying, he always runs away to another area."

**Parent:** "It does get [him] upset seeing a child crying, if it comes on the T. V he runs to another room. If he just sees a small child crying, because he thinks that all children and babies cry a lot he runs away just in case".

**Figure 5 (a): Theme 1 Antecedents of anxiety**



## Theme 2: Management Strategies

Results of the data analysis suggested that all participants utilized a variety of coping and management strategies to deal with the child's anxiety. The management strategies are listed in table 5.3. The coding system was developed and was influenced by theoretical work related to children with autism and interventions for anxiety (Dagnan et al. 2006; Joyce and Hardy 2003; Sofronoff et al. 2005; Lindsay 1999; Beail 2003). Participants described management strategies relying on the following approaches: i) Emotional, ii) Cognitive and iii) Behavioural and others, as shown in Figure 5 (b). These strategies varied in intensity of intervention from sporadic to continuous. The results of parents' interview indicate that parents cited using at least one of the "cognitive strategies" to help the child deal with his anxiety including a) talking & explaining b) visual schedule c) grading anxiety and d) stop thoughts. Participants also described using at least one of the following "behavioural strategies" including: a) Relaxation b) Distraction c) Physical activities d) Quiet-time e) Have fun f) Rewarding and g) Flooding.

***Parent** Holidays used to be a major problem, she gets very anxious. Just talking to her and showing her brochures, and reinforcing just keep doing it; keep talking to her until she does. She would go on holidays now and she is absolutely fine".*

***Parent** Hold him kindly and cuddling him, and then find out what the problem is".*

***Parent** My older son always likes listening to tapes [music], however the other one is more excited in Karate, I found it helps".*

***Parent** When he was young actually we used to build a board timetable by using pictures of the day, explaining what will happen, but now he is verbal and can communicate and use a written timetable".*

***Parent:** "Jumping in the garden, especially when it is good weather, just try to bring him out of his way [anxiety]".*

**Table 5.3. Coding of categories / identification of management strategies**

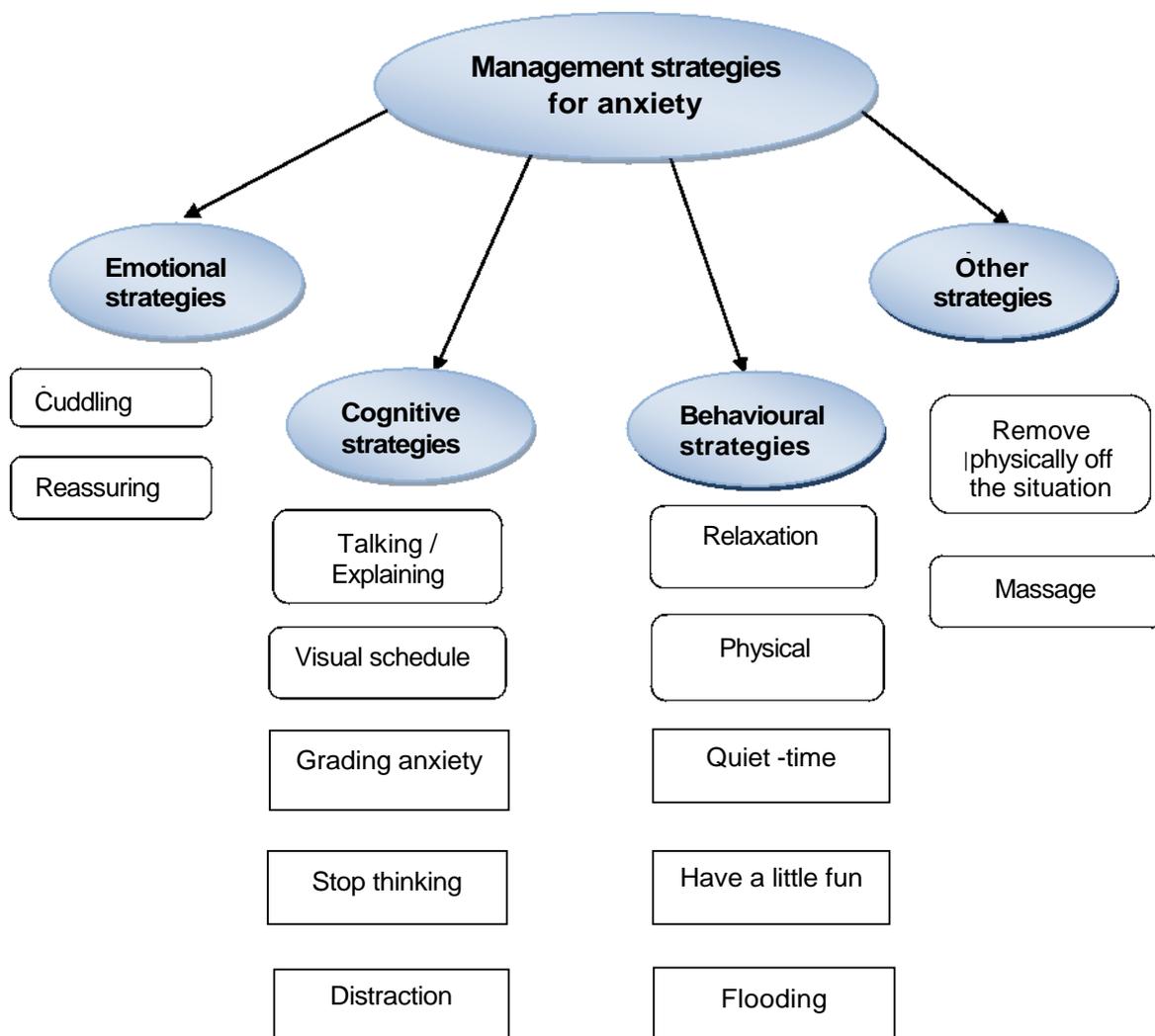
Management Strategies	Description
1. Cuddling	<del>At ease and kindly</del> cuddling him”
2. Reassurance	This is to reassure the child when he has fears or worries, e.g. “when the fire alarm went off, she got anxious. Then I reassured her, keep the language simple when you reassuring”.
3. Talking/ explaining	Talking to the child explaining the situation e.g., “He needs to tell him over and over again, talking is the most important and that is just constantly talking.” “Let him know, explain to him A to X, Y, and Z, it may take half an hour, let him know what is happening” e.g. “I do not tell him to be patient or calm down, I am just trying to explain if we are going to somewhere, and it takes only by few mints”.
4. Stop thinking	Stop thinking of this anxiety “e.g. stop and think, you might repeat that he can break something out so stop and think” I will count to three and your behaviour should change or stop”.
5. Grading anxiety	This strategy includes counting to grade their anxiety “e.g. count the grading to calm themselves down, count from 1 to 10”.
6.	<b>Visual schedule</b> / This category includes pick up cards or images for their events, e.g. timetable is effective with anxious children. <span style="float: right;">Vis</span>
7. Relaxation techniques	Behavioural attempts to reduce one’s level of physiological, muscular, and mental tension; examples of this category include deep breathing and calming music (e.g. “I started anxiety scale with some pictures of raising anxiety when he was younger, and now he has anxiety numbers which helps me, so if he is looking anxious, I am giving him knowledge: Oh what is your number?”
8. Physical activities	This category includes all types of physical activity including exercise, sport (e.g. Karate/ swimming/ horse riding, walking, and jumping) (e.g., “physical activities just try to get him out of his way”).
9. Quiet-time	Quiet time is just to stay on his own, after that he gets calmer as there was nothing going on, e.g. “the best thing is to keep him away, after a while, 20-30 minutes, it makes him calm as if nothing happened”.
10. Distraction	This category includes ignoring the situation, and / or distracting him, trying to get his interest in something else. e.g. “I take him away before escalating such a problem from the situation, to do something he enjoys”, “it was easy to distract [him] with a video, he becomes really extremely calm, you can easily pick him up”.
11. Have a little fun	This category includes activities often considered as forms of leisure, but not involving physical activity. Examples include playing a favourite game / toy, video, reading a book, watching TV, listening to music (e.g., “reading a book, explaining to the child how to explain his feeling”.
12. Rewarding	<del>Child high five</del> clap to encourage him .

**Table 5.3. Coding of categories / identification of management strategies (continued).**

Management Strategies	Description
13. Flooding	This includes facing up to the anxiety e.g. “we made her face up to her anxiety and we would take her purposely to a crowded area”.
14. Remove physically	Remove the child physically from the situation (e.g., “because the problem of autism, he not always listens to you, so I have to take him away from the situation, may be to the kitchen”).
15. Massage	Using massage
16. Reinforcing	Using rewards “Using rewards lot better”.

Note: No example is provided for strategies not reported by any of the participants.

**Figure 5 (b): Theme 2 management strategies**



Overall, participants described relying on a variety of management strategies to help children cope with anxiety. Three distinct types of strategies were identified in the management of children's anxiety. These included emotional, cognitive and behavioural strategies. All the participants described using comprehensive strategies including a variety of each type to deal with the child's anxiety. Participants cited using at least one of these types (emotional, cognitive and behavioural). Each type of these strategies served to compliment other types of management strategies.

### **Theme 3: Aims of strategies**

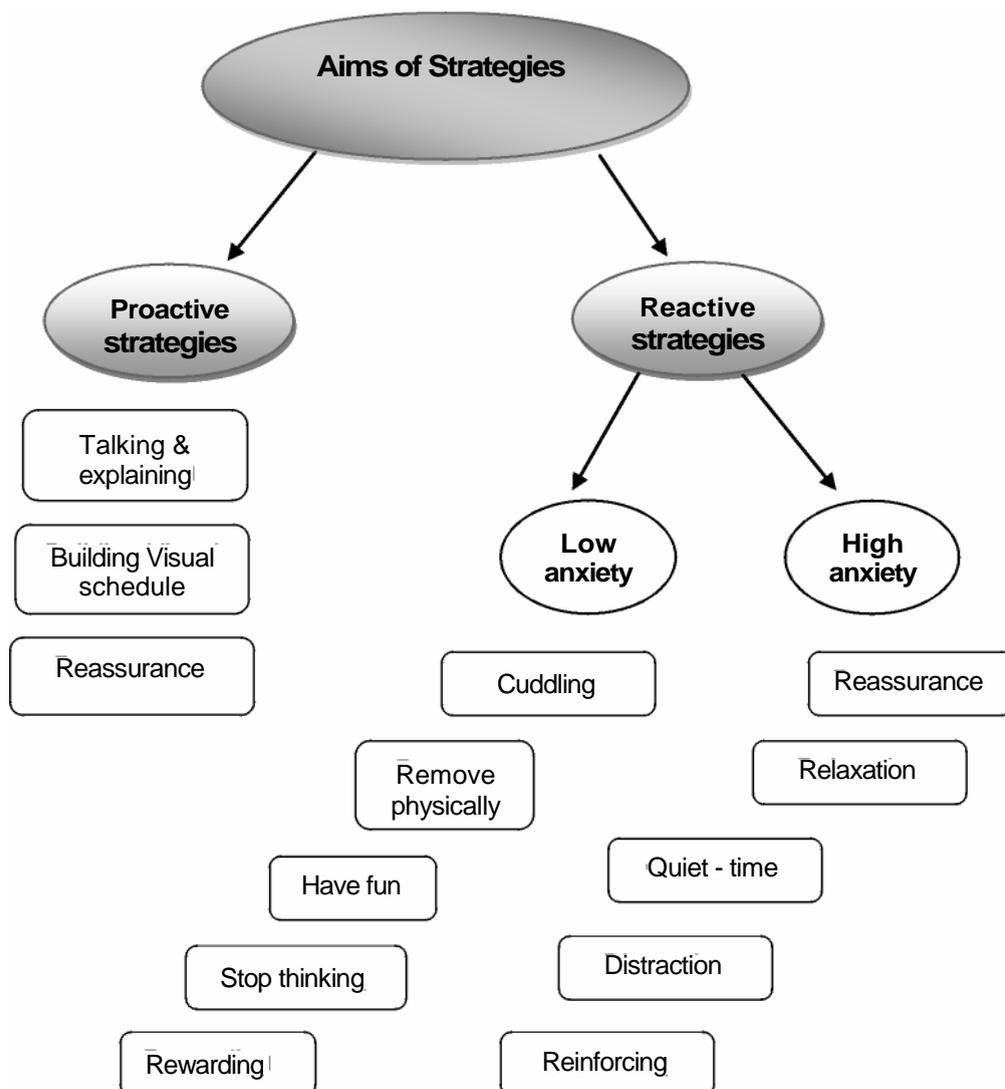
Results of the qualitative analysis suggested that parents' description of anxiety management strategies relied on the anxiety level (high / low). Thus "management strategies" were identified according to the aim of management. These strategies were grouped using a framework that consisted of: nature and intensity of anxiety (high or low level of anxiety) and aims of the various management strategies. These included: a) proactive strategies; and b) reactive strategies. The reactive strategies in turn involved two sub-categories: for low and high anxiety. All participants cited using at least one of the following "proactive strategies" to prevent triggering anxiety: talking in advance / explaining / build visual schedule (or written timetable), cuddling, and reassurance. Participants described using "reactive strategies" at different levels of anxiety to support the child before escalating its level and to help the child cope with higher levels of anxiety including: cuddling / reassurance, remove physically from the situation, diversion and distraction strategies, stop thinking, grading anxiety, relaxation techniques, physical activities, quiet-time, have a little fun, flooding, reinforcing, and rewarding, as shown in figure 5 (c). In the following excerpt, parents described using strategies that prevent anxiety escalation, as well as dealing with high anxiety:

**Parent:** Try to keep him calm before he gets angry, when gets negative it is really very very difficult to stop it which is why it takes so much effort to relax [him], not even let him to start [anxiety]”.

**3DtJnt:** “I started anxiety scale with some pictures of raising anxiety when he was younger, and now he has anxiety numbers which helps me, so if he is looking anxious, I am giving him knowledge: Oh what is your number? Are you no 1 or 2? He knows what I am talking about so he may say “No 4” which makes him more relaxed because he knows I am aware that works. But the only way to support is to let him know”.

**Parent:** “If he got number 5 on his hand [very anxious], when he was young I used to distract him. It was easy to distract [him] by video – he became really extremely calm, you can easily pick him up”.

**Figure 5 (c): Theme 3: Aims of strategies.**



In conclusion, parents, carers and teachers described relying on a variety of management strategies to help the child deal with anxiety. Individual differences and types of anxiety (high or low) were found to affect the aim of the strategies. This analysis, as briefly described, was found to encompass and explain the amount of data closely related to the management strategies for anxiety of the children.

### 5.2.7. Results 1: **Antecedents of anxiety**

#### I. Antecedents of anxiety

Results of parents, carers and teachers interviews indicated that those children and young people are more susceptible to anxiety due to different factors in their everyday life. Parents described change in routine, meeting new people, unexpected / new situations, noise, crowded places, darkness as well as worries and fears of the dentist, being afraid of dogs and cats, as triggering anxiety in children and young people. Results obtained indicated that any change in routine and noise were the most frequent factors that antecedents the anxiety for those children, as illustrated in Table 5.4.

**Table 5.4. Ranking of trigger factors for anxiety in children with autism and LD.**

<b>Factors trigger anxiety</b>	<b>Parents (N)</b>	<b>Teachers (N)</b>	<b>Total (N)</b>
1. Change in routine	9	12	21
2. Meeting new people	5	2	7
3. Noise	4	6	10
4. New situation	3	2	5
5. Babies cries	2	---	2
6. Dogs/ cats	2	1	3
7. Dentist	1	---	1
8. Busy places	1	---	1
9. Dark	1	---	1
10. Worries about future	1	3	4
11. Worries about family	---	1	1

N= numbers

## II. Management strategies

The thematic categories emerging from the data analysis of participants' descriptions provided clear examples of how parents managed the children and young people's anxiety. The results indicated a wide range of management strategies used by parents, carers and teachers. A total of sixteen different management strategies were identified by parents, carers and teachers. The findings of the interviews revealed that the most used strategies were talking and explaining. It was used by up to 50% of the parents, carers and teachers, and the distraction technique was used by 47% of parents, carers and teachers. Timetable / visual schedule was used by 41% parents, carers and teachers, however, it is noted that it has been used by teachers more in the class room than by parents.

The physical activity approach was 29.4%, included swimming, karate, horse riding, walking, and jumping. Similarly relaxation was used by 29% of parents and teachers. This technique involved listening to calming music and using breathing techniques. Reassurance was an emotional strategy. This strategy is often used by parents, carers more than teachers (44.12%). Furthermore, have a little fun (14.7%), grading anxiety (11.7%), stop thinking (8.8%), flooding (2.9%), and other strategies, for instance rewarding (8.8%), reinforcing (2.9%), and remove physically from the situation (11.7%), as illustrated in Tables 5.5, 5.6; and Figure 5 (d).

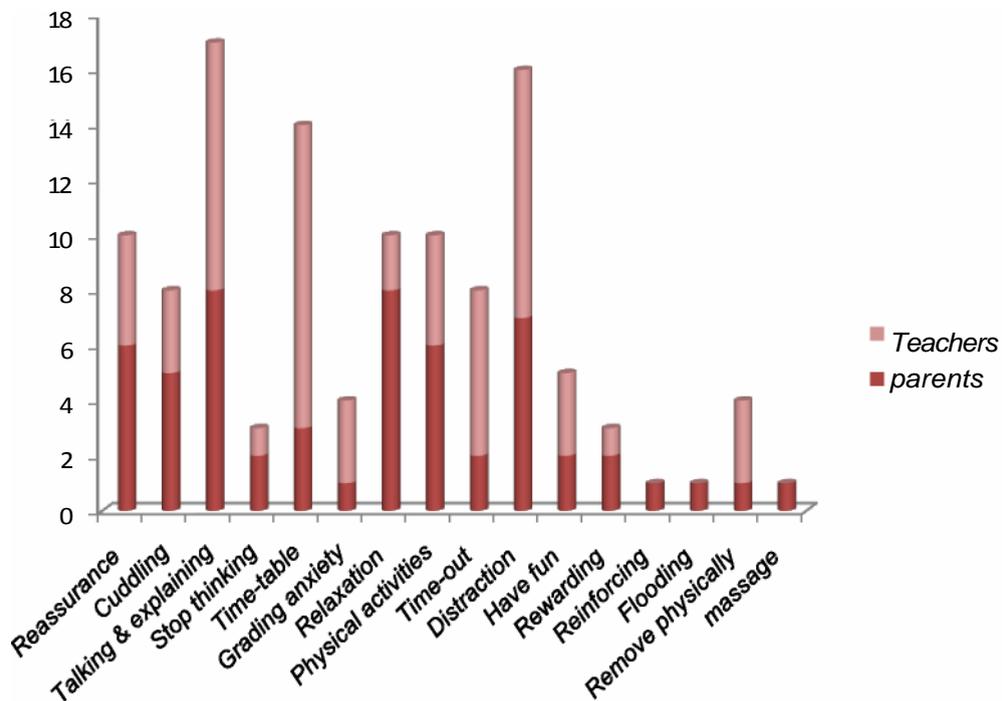
**Table 5.5. Rank orders in terms of number / percentage of management strategies used by parents, carers and teachers.**

<b>Management strategy</b>	<b>Number (N=34)</b>	<b>Percentage of use</b>
<b>1. Talking/ explaining</b>	17	50 %
<b>2. Distraction</b>	16	47 %
<b>3. Visual schedule</b>	14	41 %
<b>4. Reassurance</b>	10	29.4 %
<b>5. Physical activities</b>	10	29.4 %
<b>6. Relaxation techniques</b>	10	29.4 %
<b>7. Quite-time</b>	8	23.5 %
<b>8. Cuddling</b>	8	23.5 %
<b>9. Have a little fun</b>	5	14.7 %
<b>10. Grading anxiety</b>	4	11.7 %
<b>11. Remove physically of the situation</b>	4	11.7 %
<b>12. Rewarding</b>	3	8.8 %
<b>13. Stop thinking</b>	3	8.8 %
<b>14. Reinforcing</b>	1	2.9 %
<b>15. Flooding</b>	1	2.9 %
<b>16. Massage</b>	1	2.9 %

**Table 5.6. Descriptive statistics for management strategies.**

<b>Strategies</b>	<b>Parents</b>	<b>Teachers</b>	<b>Total No. (%)</b>
<b>Emotional strategies</b>			
Reassurance	6 (17.6%)	4 (11.7%)	10 (29.4%)
Cuddling	5 (14.7%)	3 (8.8%)	8 (23.5%)
<b>Cognitive strategies</b>			
Talking & explaining	8 (23.5%)	9 (26.5%)	17 (50%)
Stop thinking	2 (5.8%)	1 (2.9%)	3 (8.8%)
Visual schedule	3 (8.8%)	11 (32.3%)	14 (41%)
Grading anxiety	1 (2.9%)	3 (8.8%)	4 (11.7%)
<b>Behavioural strategies</b>			
Relaxation technique	8 (23.5%)	2 (5.8%)	10 (29.4%)
Physical activities	6 (17.6%)	4 (11.7%)	10 (29.4%)
Quiet-time	2 (5.8%)	6 (17.6%)	8 (23.5%)
Distraction	7 (20.5%)	9 (26.4%)	16 (47%)
Have a little fun	2 (5.8%)	3 (8.8%)	5 (14.7%)
Rewarding	2 (5.8%)	1 (2.9%)	4 (11.7%)
Reinforcing	0 (0%)	1 (2.9%)	1 (2.9%)
Flooding	1 (2.9%)	0 (0%)	1 (2.9%)
<b>Others</b>			
Remove physically	1 (2.9%)	3 (8.8%)	4 (11.7%)
Massage	1 (2.9%)	0 (0%)	1 (2.9%)

**Figure 5 (d): Descriptive statistics for management strategies**



As shown in Table 5.7, different strategies with different individuals at different ages had been use for anxiety management. As it can be seen the distraction approach (29.4%) was the most common approach used with children. While talking and explaining (29.4%) was used most with young people. Meanwhile, timetable was used equally with the two groups, but it is indicated that a visual schedule was used with children, and written timetable was used with young people.

**Table 5.7 Percentage of management strategies that used according to the age group and factors that trigger anxiety**

Strategy	Age categories			
	Children (5-12 yrs)		Young people (13-18 yrs)	
	% used	Trigger's	% used	Trigger's factors
<b>Emotional Reassurance &amp; cuddling</b>	20.6%	Specific fears( dogs, dark) change in routine, noise, new people & travelling	23.5%	change in routine, new people, pets, future, fears of water& dentist, travelling, crowded
<b><u>Cognitive</u> Talking &amp; explaining</b>	20.6%	New people, change in routine, noise, fears of dog, dark, crowed, future, holidays.	29.4%	Holidays, travelling, noise, dog, crowed, new people & change in routine, future, new situation, OCD, dentist.
<b>Stop thinking</b>	8.8%	Worries, meeting new people, noise, change in routine, travelling	0%	
<b>Visual schedule/ Time table</b>	20.6%	Change in routine, meeting new people, next situation.	20.6%	Holidays, change in routine, meeting new people, next situation.
<b>Grading anxiety</b>	5.8%	New people, new places.	5.8%	Future, going to have mental health problem.
<b><u>Behavioural</u> Relaxation technique Music</b>	17.6%	Germs, electricity, noisy, pets, meeting new people, crowds, being alone, change in routine	11.7%	Change in routine, dogs, next situation crowed
<b>Physical activities</b>	14.7%	Change in routine, dogs, new people, noisy. E.g., jumping, exercise, football, walk.	14.7%	Pets, OCD, crowed, meeting new people, change in routine. E.g. swimming, horse, walking, karate.
<b>Quiet-time</b>	11.7%	Worries, noisy, crowed, change in routine.	11.7%	Obsession, fears of water, crowd, routine, new people, noise.
<b>Distraction</b>	29.4%	Fears of dogs, worries, future, change in routine, new people, noise. E.g., get favourites, games, video, and books.	17.6%	Travelling, crowed, change in routine, noisy, worries, new people, pets, OCD. E.g., Sport, cook, smiling/ tickling/ something he interested in, quite activity.
<b>Flooding</b>	0%		2.9%	Crowds
<b>Remove physically</b>	0%		8.9%	
<b>Massage</b>	2.9%		0%	

Overall, this study highlights the key strategies that were used by parents, carers and teachers on a day-to-day basis to manage children's and young people's anxiety. Participants described relying on a variety of management strategies to help children cope with anxiety. Three distinct types of strategies were identified in the management of children's anxiety. These included emotional, cognitive and behavioural strategies. The upcoming section discusses developing a Calm Child Programme of anxiety management strategies.

### **5.3. PHASE 2: DEVELOPING A PARENTAL PROGRAMME FOR ANXIETY MANAGEMENT STRATEGIES**

#### **5.3.1. Method**

The aim of this study was to develop a parental programme of management strategies in managing anxiety for children and young people with LD and autism incorporating parents', carers' and teachers' approaches and expert panel of health professionals' views.

In order to develop a programme of consensus of anxiety management strategies, a group of health professionals with expertise in mental health problems in children and young people with learning disabilities were involved. The rationale of involving health professionals was to capture the opinion of expertise in the field of LD, autism spectrum disorders and mental health problems. The consensus was developed using the Delphi technique.

#### **Rationale of conducting Delphi**

The rationale of using Delphi technique was to discuss the strategies revealed by parents, carers and teachers with the expert panel of health professionals in order to gain the expert opinion in terms of anxiety

management strategies. The primary aim of using Delphi was to achieve consensus among panellists (Rowe & Write 1999), and is often used with health professional to gain their health expertise (Powell 2002). The Delphi technique was useful for this research to determine a consensus agreement from clinical experts for anxiety intervention on children with autism. It has been used in a number of nursing research studies (Williams & Webb 1994; Rowe and Write 1999). The Delphi approach is widely used within the health services research and professional sectors and in developing nursing and clinical practice (Jones & Hunter 1995; Reynolds et al. 2008; Langlands et al. 2008; Morrison and Barratt 2009). For example, Reynolds et al. (2008) conducted a three-stage Delphi method to explore expert opinion and develop consensus on the distinction between “research” and “audit”, and to determine the need for review by a National Health Service (NHS) Research Ethics Committee (REC). Results indicated that several ideas proved discriminatory for classifying the type of project and assessing level of ethical concern, and they can be used to develop an algorithm to determine need for ethical review. This approach has also been applied in the field of health services. The Delphi method was applied by Langlands et al. (2008) to determine recommendations on first aid for patients with psychosis between mental health consumers, carers and clinicians. The authors indicated that they obtained a high degree of consensus on a large number of recommendation items from the expert panel.

This research seeks to develop a programme based on both parents experience and health professional’s views. This Delphi approach is an effective and reliable data collection method that is particularly useful when there is little knowledge or uncertainty surrounding the area being investigated (Hardy et al. 2004), as well as for its value and its ability to structure and organize group communication (Powell 2002). These processes of Delphi were undertaken to develop a consensus agreement for anxiety management strategies in this research in order to enhance and

strengthen the intervention programme.

### **5.3.2. Delphi technique**

The Delphi technique is in essence a series of sequential questionnaires or rounds interspersed by controlled feedback that seek to gain the most reliable consensus of opinion of an "expert panel" (Powell et al. 2002; Keeney et al. 2001). The other definition is that: Delphi involves the systematic collection and aggregation of informed judgement from a potentially large group of experts on specific questions and issues in a cost and time efficient way (Reid 1988).

***The history of Delphi:*** This technique started in the Rand Corporation in the USA in the 1950s, in defence research. The name originates from the oracle at Delphi, where the ancient Greeks were said to be able to forecast future events (Rowe and Write 1999; Helmer & Rescher 1959). Gradually the technique was developed into a more established method and has been increasingly used in mainstream research in recent years (Spivey 1971; Matthews et al. 1975; Loughlin & Moore 1979 as cited in Williams & Webb 1994).

***The process of the Delphi technique:*** The Delphi survey is a group facilitation technique that seeks to obtain consensus on the opinions of experts through a series of structured questionnaires. The questionnaires should be completed anonymously by these "experts" (Hasson et al. 2000; PP. 1010).

***Expert panel:*** The Delphi seeks to gain the most reliable consensus of opinion of an "expert panel" (Powell 2002; Keeney et al. 2001). Therefore, the success of this technique requires the combined expertise of the participants who make up the expert panel (Powell 2002). The experts should be chosen

for their work in an appropriate area and their credibility with the target audience. Experts may include clinicians, researchers with scientific expertise and patients / lay people who have experience of a condition or intervention (Powell 2002; PP. 379).

*First round:* The process begins with round one. Within the classical Delphi, round one usually begins with an open-ended unstructured set of questions. That generates ideas and allows participants complete freedom in their responses. This also allows the participants relatively free scope to operate on the topic under investigation (Hasson 2000; Powell 2002). Participants are encouraged to donate as many opinions as possible so as to maximize the chance of covering the most important opinions and issues (Hasson 2000).

*Subsequent round:* The second round is made up of the analysis of the results from round one (Hasson et al. 2000). This round is seeking quantification of earlier findings, usually through rating or ranking technique (Powell 2002). For example, round two requires the data from the ratings of the items to be analysed by producing statistical summaries for each item (mean, medians and mode), to provide participants with information about collected opinion (Hasson 2000).

### **5.3.3. Recruitment of the expert panel**

A Consultant psychiatrist from Child and Adolescent services (CAMHs) at West Yorkshire was contacted, and an appointment was made to discuss the purpose of the research. In turn, the Consultant psychiatrist contacted the team working with him. Social workers, psychologists, educational psychologists and community nurses were invited to meet and discuss their experience of dealing with anxiety in the children with LD and ASD. For those who expressed an interest in taking part, appointment was made for the panel discussion.

### **5.3.4. Participants**

**The expert panel:** consisted of the Consultant of Child and Adolescent, psychiatrist, a clinical psychologist, educational psychologist and community nurse. They were recruited from CAMHs services in West Yorkshire in England. These professionals had been chosen for their scientific expertise, as they have experience of the condition and of interventions for mental health problems in children and young people with LD and ASD.

### **5.3.5. Procedure of Delphi Technique**

This research did not utilize a pure Delphi design, which would require data collection through many rounds discussion. Due to time limitation for this research a shorter version was used. The percentage and ranks of management strategies that parents, carers and teachers used with their children were presented for the expert panel, this considered as first round. Thus, the second round was developed with the expert panel of health professionals. The following procedures were conducted in this study:

The aim of Delphi was to deliver a consensus of anxiety management strategies. This was to meet with the expert panel to agree about a programme of the most useful management strategies that parents can use with their children. The thematic content analysis of the management strategies used by parents, carers and teachers was discussed. The discussion started with presenting the strategies revealed from phase (1). Sixteen different strategies were used by parents, carers and teachers. Examples of the stories of anxiety management used by parents, carers and teachers were provided to the panel. Some open-ended questions were designed to discuss with the professionals, this helped to generate the ideas of the anxiety management strategies, e.g., *“how effective, from your experience, do you feel the following strategies are in reducing/managing anxiety in young people with autism?”* The professionals were provided with the descriptive statistics for management strategies and percentage of each strategy used by parents, carers and teachers. This discussion was followed by an evaluation of the management strategies in order to get consensus

about the appropriate programme. Professionals were asked to rank the earlier findings revealed from parents, carers and teachers interviews

(Appendix- IX). This resulted in agreement about the most appropriate strategies for children with autism, and eliminated the less appropriate.

In addition, the panel discussed other strategies that may not be covered by parents, carers and teachers. This helped to maximize the chance of covering the most important opinions and issues. Each professional was asked to generate the appropriate justification for the chosen method, which helped to formalise it into a parental programme of management strategies by practitioners practising in the field of LD, ASD, and anxiety. One strategy had been modified. This strategy was grading anxiety, which parents used some cards of numbers or pictures to point to different levels of anxiety. The panel suggested that it would be a useful to arrange these levels grading from low anxiety to high anxiety. Thus, the grading anxiety was justified into the anxiety-scale thermometer. The discussion lasted approximately three hours, and it was audio recorded.

### **5.3.6. Data analysis**

Data analysis involves organizing what has been discussed, working with the data, and developing the programme.

In the first phase of this study, results revealed 16 different management strategies for anxiety were used by parents, carers and teachers. The Delphi process achieved agreement for the most of these strategies (as indicated in table 5.5). As a result ten strategies were included in the programme. These ten strategies included: 1. Visual timetable, 2. Talking and explaining, 3. Regular physical activities, 4. Relaxation approach, 5. Grading anxiety, 6. Have a little fun, 7. Distraction, 8. Quiet time, 9. Reassurance, and 10. Cuddling.

Five strategies were eliminated by the professionals, as they were not appropriate for children with LD and autism. Those were massage, flooding,

reinforcement, rewarding, remove physically from the situation and stop thinking.

### 5.3.7. Results 2: Developing a programme for anxiety management strategies

The expert panel discussion achieved a greater agreement about most of the identified strategies. There were 16 strategies were identified by parents, carers and teachers. The expert panel reached a consensus of 10 strategies. Once a comprehensive list of strategies was identified, those strategies that the expert panel of health professionals identified as effective were retained, for example, talking and explaining; relaxation; and physical activities, because they were seen as effective for reducing the anxiety. However, strategies such as massage, remove physically, rewarding, reinforcing, stop thinking and flooding were eliminated, as shown in table 5.8.

**Table 5.8. The included and excluded strategies of the programme**

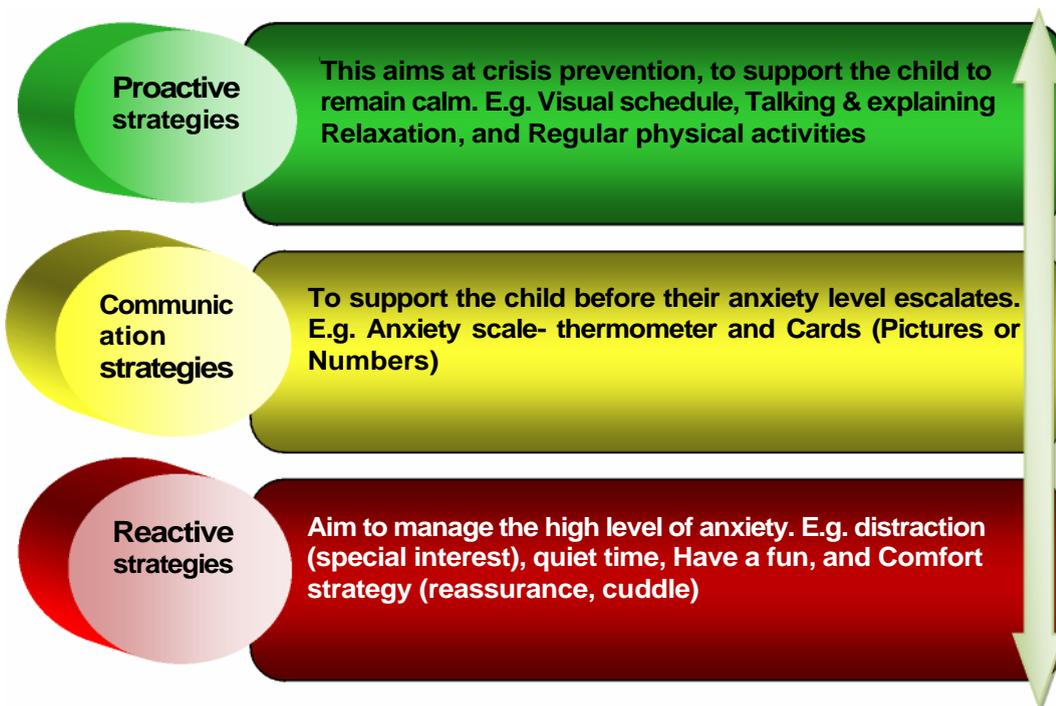
Achieved strategies	Eliminated strategies
1. Talking and explaining	1. Massage
2. Relaxation	2. Remove physically
3. Physical activities	3. Rewarding
4. Anxiety Scale Thermometer	4. Reinforcing,
5. Distraction	5. Stop thinking
6. Quiet -time	6. Flooding
7. Visual Time table	
8. Have a little fun	
9. Comfort strategy 1: Cuddling	
10. Comfort strategy 2: Reassurance	

These strategies can be categorised according to its aims. This can be exemplified with the following:

- I. Proactive strategies: the aim of this category is preventing the trigger of anxiety. As a result it is suggested that parents use these in day to day life. For instance, talking and explaining in advance or building up a timetable (visual for those who are non verbal) in addition to regular physical activities.
- II. Communication strategies: this is for parents to communicate with the child / young people when s/he started to be worried and aims to support the child/ young people and stop the anxiety escalating. It is important to parents to teach their children and young people to measure their fears. The strategy used here is the anxiety scale thermometer / anxiety numbers or cards.
- III. Reactive strategies: the focus of these strategies is to help the children and young people to cope and to manage a high level of anxiety. For example, have a little fun, distraction with the child's best interest, relaxation, comfort strategy (cuddling and reassuring). The parental program is illustrated in figure 5 (e).

**Figure 5 (e): Programme of Management strategies for anxiety.**

The developed programme is called the “**Calm Child Programme**”. The



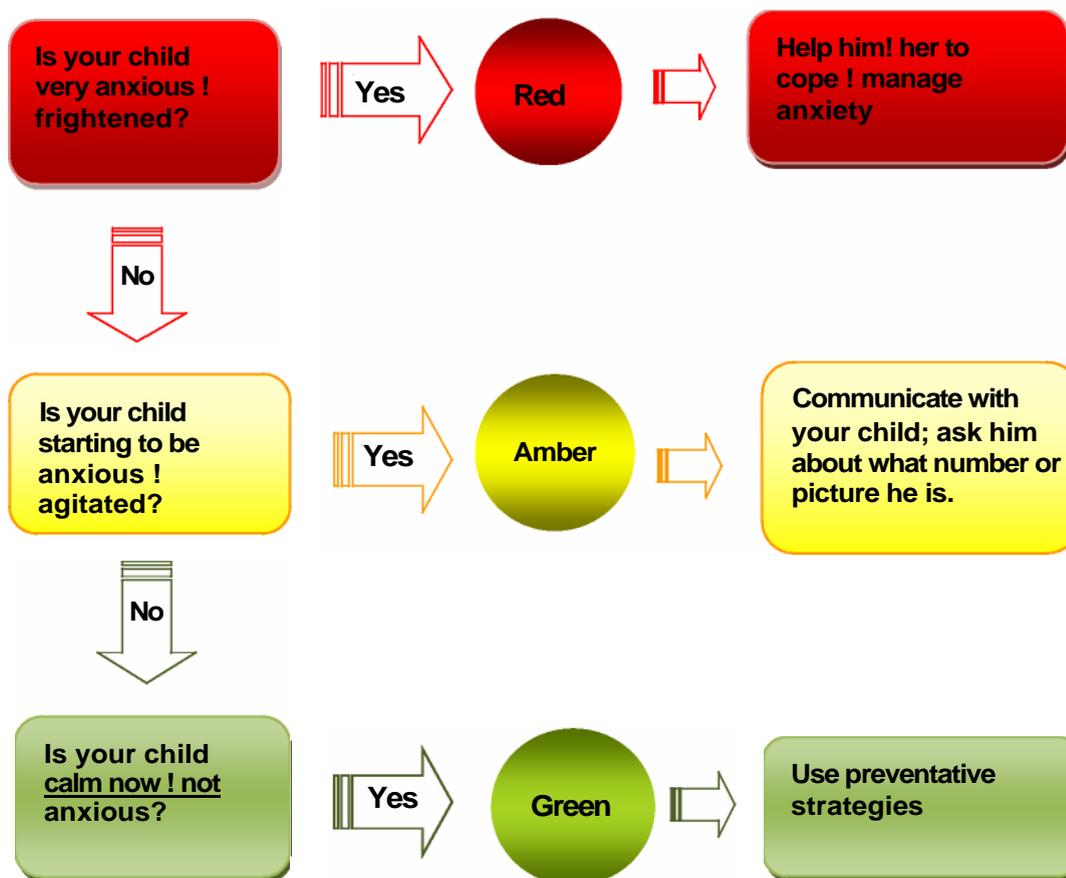
Calm Child Programme was developed using the Delphi method to identify a consensus between professionals. Comprehensive information of the strategies were provided on the parent’s information booklet. This information booklet included: general information regarding the programme and the anxiety in children with LD and autism; anxiety management strategies. In addition to top tips that will help parents to manage child’s anxiety.

Overall, professionals and the researcher agreed on the parent’s information sheet, in terms of the strategies and information that should be provided to parents for implementing the Calm Child Programme. In order to explain these strategies to parents in an easy and simple way, the management strategies were designed as a “traffic light” system to help parents determine the child’s anxiety level and how to easily find the appropriate strategies.

The following sections will discuss this traffic system.

- The “GREEN” light refers to strategies that parents might use most of the time when the child/ young people is relaxed.
- The “AMBER” means strategies parents might use once they notice their son“s / daughter“s anxiety, and this is for parents to determine the anxiety level of the child.
- Lastly, the “RED” light should be used when parents identify the child is anxious. This traffic light system is presented in Figure 5 (f).

**Figure 5 (f): Traffic light system**



## I. .onElit1-EVAMoA1-111-VETEGU1-1-QE1.1KA'E

The Green light strategy is a proactive approach which aims at crisis prevention. The focus is on supporting the children / young people to remain calm and for parents to be one step ahead. Parents are asked to use these ideas most of the time, day by day in order to reduce the child"s/ young people"s anxiety. Strategies included in this level are:

### 1) **Visual schedule**

The visual schedule or timetable uses pictures as a means to support the child/ young people to cope with change. Children and young people with autism are more sensitive to any change in their daily routine. So this visual timetable helps to reduce anxiety because it helps them to understand what they are going to do during their day. A visual timetable makes time concrete, allows a child to see time passing, and to see plans for the future. For most children, the timetable is arranged from left to right. For some children and young children, a top to bottom format may be more understandable.

### 2) **Talking and explaining**

Parents are advised to constantly talk to their children/ young people in very simple language about what s/he is going to do. Parents need to talk over and over again about the situation and let the child/ young people know what is happening, from A to X, Y and Z. The basic rule for parents is to be clear, concise, and consistent. Also explain in advance any out of routine events, like holidays, using brochures and leaflets for the place you are going to visit. This should also be the case for a trip with the school, or school shopping trips.

### 3) Regular physical activities

Physical activity is very good for children and young people, particularly if they are very agitated. Activities that other parents have found helpful are:

- Get outside and do some exercise, such as running in the garden, swinging.
- Going for a walk, a short walk in the fresh air can help him feel good, or perhaps for a long walk with the dog.
- Jumping on a trampoline.
- Special regular activities: e.g. swimming, Karate, horse riding, football, dancing.

### 4) Relaxation

For parents: help your child/ young people to relax. Firstly it is important to create a relaxing environment choosing a comfortable, quiet and peaceful room. It may be possible to teach your child/ young people how to relax as a coping skill when s/he becomes agitated or angry. There are many ways to help him/ her to relax including:

*Breathing technique:*

For example deep breathing, to take time to breathe slowly and deeply and count 1 to 10, as this can help them feel calm. Also practice some breathing exercises, for example ask your child / young people to imagine there is a balloon inside his chest and then breathe out and let all the air out.

• *Listening to relaxing music:*

Music can stimulate and develop more meaningful and playful communication in people with autism. Music can also play an important

role for children / young people with autism in developing positive interactions. For example you can use calming music every time before bedtime.

- *Reading books:* e.g. books explaining to the child / young people how s/he can express their feeling.
- *Warm bath in low lighting:* may help your child to feel calmer.

## II. &RP POnIFClea/ IIKayROraFKIWaaC( 11IICaI\$ P EFU

It is essential to parents to talk to the child and to gain his / her view of the situation. Children may be able to describe their fears or anxiety and the situations which give rise to them. This communication is likely to be helpful. If the parent noticed his son / daughter appeared worried or agitated, then there is an opportunity to start to communicate with him / her. So parents might tell him that they notice he looks anxious. For example, “Are you alright?” Or “How do you feel?”

Here are some ways to help your child to tell you more:

### 5) Thermometer approach

Parents may present the thermometer of anxiety rating scale to the child / young people and ask him to show which number he is. For example, how worried are you? Can you show me? Are you a 2 or a 3? (Anxiety scale thermometer is presented in Figure 5 (g)).

**Figure 5 (g): Anxiety Scale Thermometer**

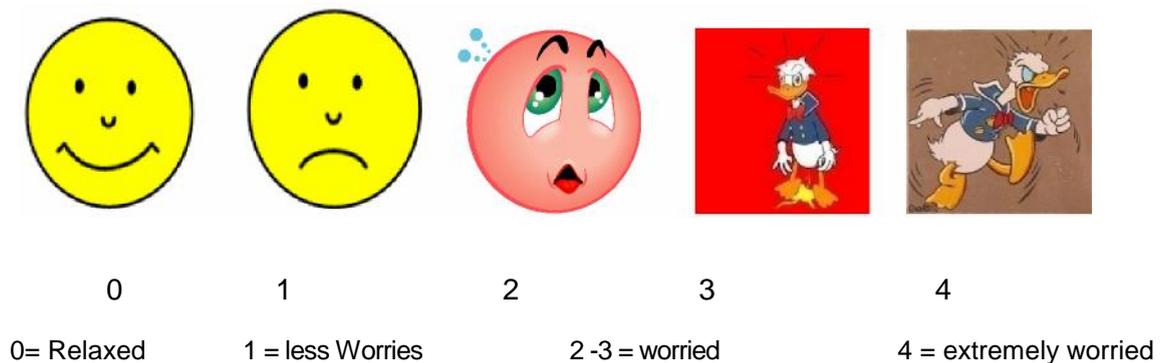


Parents can use pictures to help the child / young people tell them about their feelings. The parent might ask his child/ young people to draw pictures that make sense to them. Examples present in figure 5 (h) and 5 (i).

Figure 5 (h): Example1 card numbers



Figure 5 (i): Example 2 card pictures



### III. 5 HDcA4WH VAMDAHU IHV1 5 HG

This category is for parents to use when the child or young person is agitated or feeling anxious, and there are a number of ways to help them to cope with anxiety. For example:

#### 6) Have a little fun

Having fun is a great way to increase good feeling and release tension. Getting in touch with fun and play is often easier for children than for adolescents. Sharing fun with the child is often helpful to release his fears or

worries, for example play his favourite games, try some painting. Children can also express their feeling by drawing.

### **7) Distraction (special interest)**

One way of helping a child to cope with his anxiety is to make use of his particular interest. When parents find his son / daughter agitated, ignore the situation and try to distract the child before his anxiety escalates. The trick here is to let him/her do something he enjoys e.g., watching his favourite DVDs, playing favourite games, jumping, drawing, feeding the birds, his favourite toy.

### **8) Quiet -time**

Quiet time gives children the chance to have time to manage themselves. This gives them the chance to calm down. The time given should be kept to 1 minute for each year of age although this can be repeated. A quiet, stimulation-free spot is a good choice. Some children ask for quiet-time for themselves.

### **9) & 10) Comfort strategy (reassurance & cuddling)**

Parents can offer physical expressions of love for their child to help to calm them down. Simply placing hands on the back or holding hands can be very relaxing. Parents will know what areas are most sensitive for their child and so avoid them. Parents may need to find out what sort of touch or holding gives most comfort for their children.

### ***Final stage of Delphi***

As it is quite useful as it discussed before in the Delphi process to evaluate the final programme with the expert panel. Thus, after two weeks of meeting with the expert panel, the researcher contacted the professionals, sending

the parent's information booklet that was agreed for review and evaluation of its validity and applicability for parents.

### ***The applicability of the programme***

The final draft was sent to some parents who had been interviewed in the first phase of this study to check its applicability for parents. The aim was to find how much this programme was understandable by the parent. It is important to note that there was no changes have been identified for the information booklet after parents' feedback.

## **5.4. CONCLUSION**

The focus of this study was to gather qualitative information about parental management strategies of anxiety in day to day life among children with LD and autism. This was to develop a parental programme which identify consensus between professional of management strategies for anxiety. 34 parents, carers and teachers of children with autism and LD were interviewed regarding the management strategies for child's anxiety. Exploration of the stories of management strategies helped to build the typologies of strategies used by parents, carers and teachers. The results indicated that a wide range of management strategies were used by parents, carers and teachers. On average sixteen different strategies were identified from parents, carers and teachers' interviews. The numbers of strategies used varied as a function of the child's age and type / severity of anxiety within the autism spectrum to manage child's anxiety. Management strategies were identified as emotional, cognitive, and behavioural approaches.

The Calm Child Programme was developed with an expert panel of professionals using the Delphi technique. Health professionals identified ten appropriate strategies for those children and young people. Finally, a

parental programme of strategies was developed based on parents’ experience and the panel discussion. The developed programme is called “Calm Child Programme”. This programme will be implemented with a small sample of parents of children and young people with LD and autism, which is discussed in the next chapter.

# ***CHAPTER 6: IMPLEMENTING THE CALM CHILD PROGRAMME***

## **6.1. INTRODUCTION**

This chapter discusses the methods of implementing the Calm Child Programme. A pilot study was conducted with a small group of parents of children and young people with LD and autism. The aim was to implement and evaluate the Calm Child Programme of anxiety management strategies.

## **6.2. METHOD**

### **6.2.1. Recruitment of the participants**

Parents of children and young people with LD and autism were invited to participate in this study. Some parents from the screening study were contacted and asked if they would like to take part in this study. In addition, new parents were recruited through advertisements and the newsletters of the autism support groups at West Yorkshire and North East of England and through Special Education Schools. The parent's invitation letter (Appendix-XIII) was sent to these organisations and services. They were asked to distribute this letter to parents for involvement in the study.

Eligibility criteria for this group of were based on parents caring for:

1. Children with LD and diagnosed with autism and aged 5 – 18 years.
2. Children with anxiety scores from the anxiety rating scale.
3. Children not concurrently in any other treatment or appropriate intervention for anxiety as identified by the parents.

Twenty parents initially expressed an interest to participate in the study. These included some parents from the initial sample of the screening study (Yorkshire families) and additional parents from the North East. Parents who met the above criteria were eligible to take part in this programme. Parents who agreed to participate in the study were contacted by telephone where all their enquiries regarding the study were explained. The information pack was posted to parents. This information pack included: the Calm Child Programme, GAS-ID scale, parents' diary, consent form, and an example of visual schedule.

Before starting the study, twelve parents were excluded. Reasons for this included: parents used similar strategies, the study was not appropriate with their children, personal circumstances, while the rest failed to be contacted. Finally, eight families started and carried out the programme. During implementing the programme there was one dropout. One of the participants dropped out after 4 weeks because the child was nonverbal and the parent was not able to communicate with him. At the final stage this study was carried out with seven families of children with LD and autism. The pilot study was conducted over a period of 3 months (13 weeks).

### **6.2.2. Participants**

Seven parents of children with LD and autism were involved through to the end of the study. Mothers were aged between 25 and 49 years, and they were parents of seven children (6 boys, and 1 girl). The children ranged in age from 5 to 14 years and the mean age was 9.04 (SD= 3.05) when the programme started. The majority of children were male (85%), and had mild LD and autism, although one case was diagnosed with Asperger's syndrome. All the children and young people lived at home with their parents, and studied within Special and Mainstream Schools. 43% of the children (N=3) were in mainstream educational provision, and 57% of children (N=4) attended a Special School for children with LD. Participants' scores on the

GAS-ID were used to select children to be invited to participate in the study (which included those children from the original sample). The mean GAS-ID anxiety scores were 27.29, SD = 5.3. Those children who scored within the minimal anxiety range and above were eligible to take part in the study. The GAS-ID anxiety scores for the participants ranged from 20-34 (cut-off = 20). Table 6.1 summarizes the characteristics of the children.

**Table 6.1. Characteristics of the children and young people**

Case No.	Diagnosis	Gender	Age (years)	School type	Anxiety T1* score
1	autism & LD	M	8	Mainstream	33
2	autism & LD	M	14	Special	24
3	autism & LD	M	10	Special	34
4	Asperger's & LD	M	9	Mainstream	20
5	autism & LD	F	6	Mainstream	27
6	autism & LD	M	11	Special	23
7	autism & LD	M	5	Special	30

T1 = GAS anxiety level at the start of the study.

Consent was obtained through the following process: The families who expressed an interest in participating were provided with more information about the study, including the purpose of the study, who the researcher was, what would happen if they took part, what were the possible benefits of taking part, and other information that they might have found useful to make the decision in order to participate. The information leaflet is presented in Appendix (XIV). All participants signed informed consent prior to commencing the programme, this included consent for implementing the programme, completing the GAS scale, and the focus group. All participants were informed of the procedures in place to preserve their confidentiality. All participants were informed of their right to withdraw from the research at any time and that withdrawal from the study would not affect their legal rights.

## **6.3. MEASURES AND INSTRUMENTS**

### **6.3.1. GAS-ID:**

The Glasgow anxiety scale for children with intellectual disabilities: GAS-ID (Mindham and Espie 2003) was used. This scale is described in detail in chapter 4, PP. 122.

### **6.3.2. Focus group:**

Focus groups help to generate key issues (Morgan 1997). A focus group is a group interview on a specific topic; which is where the "focus" comes from. It is an open-ended group discussion guided by a moderator. The focus group was conducted with the participants implementing the Calm Child Programme to identify the usefulness and the impact of the information booklet of anxiety management strategies.

## **6.4. PROCEDURE**

The information pack was to send to parents by post. This information package contains: the Calm Child Programme, consent form, two copies of the GAS-ID scale, parent"s monitoring diary (Appendix - XIX), and examples for visual timetable (Appendix - XVII). The outline of the programme is described in (Appendix - XII). Comprehensive information of the strategies were provided in the parent"s information booklet, the "Calm Child Programme". Parents were asked to monitor the child daily in a monitoring diary to record the practice and outcomes from practicing the strategies themselves. Participants were telephoned within a few days of posting the information pack to ensure its receipt. After parents received all the information, the researcher contacted the families and explained the purpose and nature of the Calm Child Programme, answering their questions. Parents were assured about confidentiality issues. All participating parents gave their

written consent for their participation prior to start, completed the GAS-ID and posted them back to the researcher. A total of seven families completed the implementation of the Calm Child Programme. Parents were contacted by telephone every fortnight to follow up. They informed the researcher with the children's progress of managing the anxiety. In addition, parents were informed that the researcher was available to answer any questions in relation to the interventions specified in the calm child programme, and they were welcome to contact her at any time if they have any concerns about the interventions and strategies they have chosen to adopt. At the end of the implementation period of 3 months, parents completed the GAS-ID and the evaluation for the programme (see parent's evaluation sheet in Appendix - XX). The participating parents were asked for their feedback. As a consequence, a focus group was organised at the end of implementing the Calm Child Programme to discuss the usefulness of using these management strategies.

### **Procedure for GAS**

Differences between pre- and post-intervention were examined using the GAS-ID. Assessment was conducted prior to implementing the strategies. In addition, a repeat assessment for anxiety was conducted at the end of the 3 months. Parents were asked to complete the GAS-ID scale to compare the differences of anxiety scores before and after using the strategies. Moreover, parents were asked to make a daily diary (Appendix - XIX) entry to record the practice and outcomes from their experience of using the strategies as well as a focus group conducted with parents after the 3-month period. The GAS-ID was used to assess the anxiety in children in this study. A combination of Reiss and GAS-ID was not used in this study, because the aim was to assess the anxiety only and not related mental health problems.

## **Procedure for focus group**

Focus group was conducted in order to explore parents' experiences of implementing the Calm Child Programme of anxiety management strategies. After completing the intervention, parents were contacted to arrange for a focus group to discuss the implementation and usefulness of using these management strategies.

Conducting focus groups with parents posed particular challenges to the researcher. There were some difficulties in recruiting the participants and conducting the focus group with the seven participants. The participants were recruited from two different regions in the UK (four from North East and three from West Yorkshire). Four parents of the seven participants attended the focus groups. For the North East group one of the participants was not able to attend the focus group and another parent was not contactable. Due to personal circumstance one of the participants from the West Yorkshire group was not able to attend the focus group. For those parents who were not able to attend the focus group, the researcher sent out an evaluation form by post for their feedback. . Hence, there were only two participants for each of the focus group meetings. The aim was to conduct a focus group. However, owing to the small numbers a discussion was conducted with both individuals attending the group, using the focus group guidelines. The small group discussion was useful to obtain in-depth information from the participants and having the opportunity for participants to get fully involved in the discussion.

Two group discussions were conducted in a mutually agreed upon location (one focus group for West Yorkshire participants, and the other for the North East participants). The first group was held at Children and Adolescents Mental Health services (CAMHs) at West Yorkshire, and the second focus group was held at the interview room at Northumbria University. Each focus group comprised of a group of two participants and a moderator (the researcher). Interviewees were assured of confidentiality and the process by

which their confidentiality would be safeguarded (as described in the methodology chapter 3). All interviews were audio recorded and transcribed.

The group discussion initially started with a friendly welcome to the interviewees and warm-up. The researcher then outlined the confidential nature of the interview and its time constraints. This was followed by gaining permission to tape record the interview. Verbal consent had been taken for audio taping for the purpose of the transcript, as informed written consent had been taken before commencing the study, including conducting the group discussion.

During the group discussion: once the first participant responded, all participants had the opportunity, in turn, to give thoughts on the questions posed. Each participant responded to the questions “without interruption” from others. When all the participants responded there was an opportunity to engage and ask others regarding their experience (enabling interacting between participants). Then the discussion covered the main questions regarding the implementation of the management strategies. These questions were:

- *I would like to discuss with you experience of using these strategies. As you know the strategies presented three categories underneath: Red, Amber, and Green. Let us start with the daily life strategies (green light): visual schedule, talking and explaining, regular physical activities, relaxation. How did you use these strategies? How often do you use them (daily or weekly)? What did you find out of using any of these? What about other strategies!! (for example Physical activities, what kind of activities? Which of these strategies did you use most often?*
- *Let us move to the amber strategies (communication with your child): did you implement this approach? How many times did you use it? Have you found this thermometer effective in communication with your child?*
- *Thirdly, turn to the red light strategies: we have here 5 strategies: have a little fun, distraction, quiet time and comfort strategies. Which one of these you found more positive on helping your child to manage his anxiety? How did you*

*implement each one of these strategies? How many times did you use? And what is its effectiveness?*

- *Well, now we finished our talk about the strategies you used, I would like to ask you about overall the programme.*
- *What is strategy do you think was more effective for dealing with your son "s/ daughter "s anxiety?*
- *Which strategy have you not used? Why?*
- *Do you think you will need to carry out any of these strategies in the future? Which one? And for how long you need to carry it out?*
- *Can you list the changes you have seen in your son / daughter before and after using management strategies for anxiety?*

After the open-ended segment of the interview, participants were asked if there was anything that they would have liked to add, to help ensure no relevant information was overlooked or forgotten *"Can I finally ask you if you think there is any aspect of your experience of looking for treating / managing anxiety that has not been covered in this group discussion?"*.

Lastly, at the end of the group discussion participants were thanked for their participating in this research. The group discussion lasted around 90 minutes, and was tape recorded. See Appendix - X for the group discussion schedule.

## **6.5. DATA ANALYSIS**

In analyzing the differences in children"s anxiety before and after using the developed programme of anxiety management strategies, quantitative and qualitative data analyses were used. Descriptive statistics were used for analysing the results. In addition, Wilcoxon test (non-parametric statistics of a related sample) was conducted in order to examine the differences of the child"s anxiety pre and post intervention. Thus, it allowed evaluation of the impact of using the Calm Child Programme in reducing the anxiety level in

children, comparing GAS-ID scores pre- and post- implementing the management strategies” programme.

Qualitative data from the group discussion were analysed using content analysis. This aimed to identify the effectiveness of using the anxiety management strategies on the parents” discussion.

## 6.6. RESULTS

### 6.6.1. GAS-ID

The anxiety scores of children were compared at pre- and post-test programme implementation of the Calm Child Programme. A repeated measure of anxiety after three months of applying the strategies was performed in order to determine any changes to the anxiety level over time. Table 6.2 shows children”s anxiety scores at the two points (T1= time one pre- intervention and T2 = time 2 post- intervention). Descriptive data (means and standard deviation) for the participants at two point assessments, pre- and post-programme, are presented in table 6.3. The results showed that children”s anxiety mean scores after the programme were (M=16.43; SD=3.599) lower than the anxiety mean scores before the programme (M= 27.29; SD= 5.282). It can be inferred that the mean of anxiety scores decreased 10.86 points at the post-intervention.

**Table 6.2 Results of Glasgow Anxiety Scale pre-and post-intervention**

Child Code	Pre- intervention score (T1)	Post- intervention score (T2)
1.	33	18
2.	24	16
3.	34	22
4.	20	13
5.	27	11
6.	23	17
7.	30	18

(T1= time one pre- intervention and T2 = time 2 post- intervention)

**Table 6.3 Descriptive data for the study participants on GAS-ID scale.**

Anxiety scale	Pre-test		Post-test	
	M	SD	M	SD
GAS-ID	27.29	5.3	16.43	3.6

**Figure 6 (a): The anxiety scores pre and post programme**

NB: T1 = time one pre-intervention, and T2 = time 2 post- t intervention

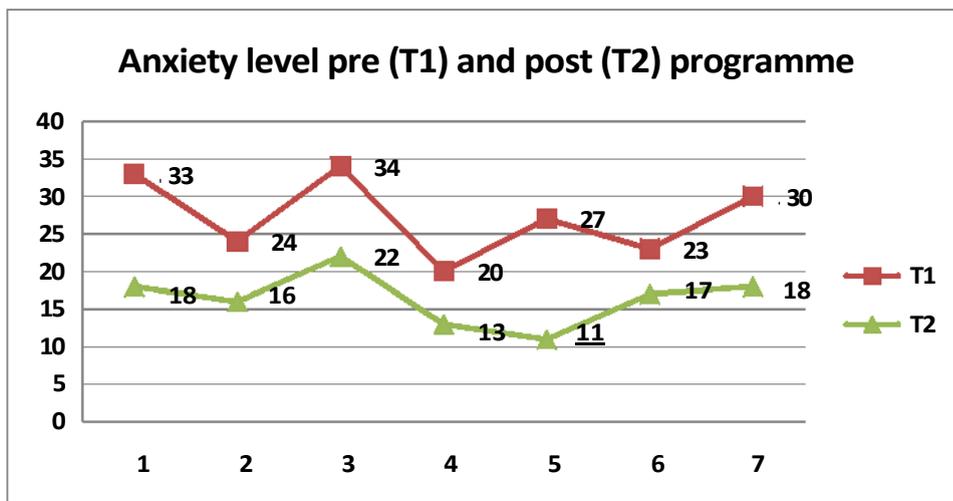


Figure 6 (a) shows the anxiety scores on the GAS-ID at each time point for children after using the management strategies for the 3 months. All children showed a decrease in the anxiety score at (T2) after the implementation of the programme. In most cases (85%) anxiety score decreased to be under the cut-off point (=20) on GAS-ID. One case anxiety reduced but remained 2 points above the cut-off, (case No.3, see table 6.3). A related sample Wilcoxon test was used to examine differences in anxiety scores pre- and post-test for children,  $Z = -2.371$ ,  $p < .05$ . There were statistically significant differences of children's anxiety between pre- and post-test using the Wilcoxon test.

**Table 6.4. Willcoxon Test Statistics <sup>(b)</sup>**

		Gas2 - Gas1
Z		-2.371 <sup>(a)</sup>
Asymp. Sig. (2-tailed)		.018

a Based on positive ranks. b Wilcoxon Signed Ranks Test

### **The pen picture for the children of the pilot study:**

#### **Child 1**

This child was a 8-year-old male with mild autism and mild LD. He lived with his parents at home in West Yorkshire. He was attending Mainstream School. Parents indicated that his anxiety is the most disabling problem of his autism. The Calm Child Programme (CCP) was implemented by the mother (age range 35-49). GAS-ID scale presented that he had high anxiety score (33) before implementing the CCP. The GAS-ID score indicated that he worried a lot and had worries about the family and death. He worried that something awful might happen, he was also anxious of changing routines and doing something new. He was also scared of darkness, meeting new people, and being in busy places and was frightened of dogs. Anxiety improved markedly after three months of implementing the CCP. The GAS-ID post-test anxiety score decreased from 33 to 18. The most useful strategies as reported by the mother were distraction and physical activities.

#### **Child 2**

This was a 14-year-old male diagnosed with moderate autism and borderline LD. He lived at home with both parents in West Yorkshire. He was attending Special School. The CCP was implemented by the mother (age range 35-49). GAS-ID anxiety scale indicated that he presented worries regarding something awful might happened to him, and he worried about death. He was anxious about changing routines (holidays and visitors), he worried about what will happen tomorrow and also of doing something new. In addition, he was also scared of spiders, felt anxious in busy places and meeting new people and visitors, and was scared of going to the doctor or

dentist. His anxiety score before starting the programme was 24 on GAS-ID, and this anxiety improved markedly to 16 (T2), after implementation of the CCP for 3 months. The most useful strategies as reported by the mother were regular physical exercise plus intensive exercise when he was highly anxious, in addition to distraction and painting.

### **Child 3**

This child was a 10-year-old male diagnosed with moderate autism and mild LD. He was attending Special School in West Yorkshire. He lived with both parents at home. The GAS-ID indicated that he had lots of thoughts and different worries about his parents, doing something new, something awful might happen, and death. He was also scared of darkness, and was frightened of lifts or escalators, busy places and wide open spaces. The CCP was implemented by the mother (age range 35-49). His anxiety was high before starting the programme (T1 = 34) on GAS-ID. However, his anxiety improved markedly (T2 = 22) after implementing the CCP. This was the only child whose anxiety level was reduced but remained 2 points above the cut-off point on GAS-ID (=20). The most useful strategy found by the mother was physical activities, and visual schedule.

### **Child 4**

He was a 9-year-old male with Aspergers<sup>™</sup> Syndrome and borderline LD. He attended mainstream school. He lived with his parents at home in North East England. The CCP was implemented by both the mother and the father (age range 35-49). GAS-ID anxiety scale indicated that he had great worries about death, if he felt unwell and worried that something awful might happen. It is also indicated that he was anxious about doing something new. The anxiety score before starting the programme was 20 on GAS-ID. Anxiety improved markedly to 13, after implementing the CCP for 3 months. The most useful strategy as reported by the mother was distraction with the special interest of the child.

### **Child 5**

This child was a 6-year-old female, diagnosed with mild autism and mild LD. She was attending mainstream school. She lived with both parents in the North East of England. The CCP was implemented by the mother (age range 35-49). Anxiety as assessed by GAS-ID before implementing the programme indicated that she had worries particularly about the family and her parents. She was also worried about doing something new, and about tomorrow and the future. She also presented fear of dogs and being up in a high building. Anxiety improved markedly after her mother implemented the CCP for 3 months. Her anxiety score before starting the programme was 27 on GAS-ID, and decreased to 11. The most useful strategies as reported by her mother were talking and explaining, distraction and physical activities.

### **Child 6**

This child was an 11-year-old male with mild autism and mild LD. He lived with his parents at home in the North East of England. He was attending Special school. The CCP was implemented by the mother (age range 25-34). GAS-ID anxiety scale indicated that he presented worries about doing something new, what will happen in the future, and worries about the family. It is also indicated that he was anxious about doing something new. It is also indicated that he was anxious in busy places and meeting new people. Anxiety improved markedly after his mother implemented the Calm Child Programme for 3 months. His anxiety score before starting the programme was 23 on GAS-ID, and decreased to 17 (T2). The most useful strategies as reported by his mother were talking & explaining, and distraction.

### **Child 7**

This was a 5-year-old male with autism and moderate LD. He lived with his mother at home. He was attending Special School in the North East of England. The CCP was implemented by the mother (age range 25-34). GAS-ID anxiety scale indicated that he was anxious about changing his routine, meeting new people, and also about the future.. His anxiety improved markedly after 3 months of implementing the CCP. Anxiety score before

implementing the programme was 30 on GAS-ID, and this anxiety decreased to 18.

### **6.6.2. Focus group**

A group discussion was arranged with parents, which aimed to relay key findings from the study, and to give participants opportunity to consider how these strategies were helpful to their children / young people and for them. The group discussion included discussion of Calm Child Programme that they used with their children / young people during the last 3 months. The group discussion revealed the nature of the parents' experience to manage their child's / young people's anxiety.

The results obtained from the group discussion and parents' monitoring diary indicated the most effective strategies that parents found useful with their son / daughter. These were distraction (with special interest), physical activities and talking & explaining. The most frequently reported used strategies were physical activities, distraction, talking and timetable (visual or written) in sequence. The majority of parents used a combination of these different strategies to manage the child's anxiety. These findings are discussed in greater detail below:

#### **I. Proactive strategies and their effectiveness**

Regarding the prevention level strategies, talking & explaining, physical activities, and timetable were the most used strategies by parents.

In an effort to manage the child's anxiety due to a change in routine, for instance going on holidays, parents used talking and explaining in advance as a strategy to help prevent trigger the child's anxiety. Parents practiced implementing this strategy by having visual descriptions, written plans or

brochures about the place they were visiting with their children / young people so that they could prepare for this routine change. The following quotes are examples of participants' strategies that they had already been practicing with children's / young people's anxiety in their lives:

**Parent:** *"Talking and explaining I do all the time consistently, it is essential really" (Child 4).*

**Parent:** *"I've started writing in data for going on a holiday or going for a weekend. Writing out data of what you're going to do, and giving that to him, you know, even if I've said it, he might need it written down, and [he] looks at it, reads it many times and takes it with him, and it helps reassure him and even he knows what is in it he keeps on looking at it and he became calm from this" (Child 2).*

Using a timetable to plan a child's / young people's day to day activities was also a helpful strategy to prevent developing anxieties.

**Parent:** *"I started to make visual timetable, and to talk with her about what will happen. It helped her to understand" (Child 5).*

**Parent:** *"We do use which is the written down [timetable], and he has a calendar. He is writing his own things next to it as well. He keeps looking at it, and even he knows exactly what is happening tomorrow, he still wants to look at it again and again and again. Just for reassurance you know. He thinks it might change, it seems he has not too much confidence in the future, that it might change even if it is planned" (Child 2).*

Parents reported that the "physical activities" strategy proved very helpful in managing anxiety. Physical activities involved walking, running, sitting up, swimming, trampoline, and hand exercise. In addition to children practicing regular physical activities, they implemented some exercise when necessary, or when they were feeling anxious. Some of the parents' narratives were:

**Parent** *Physical exercise works extremely well for my son" (Child 4).*

**Parent** *My son does run every day, and does sit ups every day but if he is feeling specially anxious he goes and does extra ones, he does it very fast and says: Oh I've done it 100 steps and I feel better now" (Child 2).*

**Parent** *we have a dog, he likes to go for a walk [with the dog], I think that helps to calm him down you know” (Child 3).*

**Parent** *I started to take him for a walk around the village at the end of my work. And now he’s started to go with his own, and he has his own route now” (Child 2).*

Overall, parents illustrated that proactive strategies proved very useful in managing the child’s / young people’s anxiety. Physical exercises were reported as the most often used strategy in the proactive level. Parents were implementing these strategies in an effort to prevent triggering anxiety.

**Parent** *“I do very very hard for these [proactive] strategies to not go for the amber [low anxiety] or the red level [high level of anxiety]” (Child 3).*

## **II. Communication strategies**

In these types of strategies parents were encouraged to acknowledge the children’s anxiety and to start to communicate their anxiety signs with an Anxiety-scale thermometer, and anxiety numbers or pictures, or by asking children to draw pictures.

**Parent** *she drew her pictures to express her emotions, this makes sense for her” (Child 5).*

Parents had concerns regarding the anxiety-scale thermometer approach. They thought that the child did not tell the truth when the parent asked the child about their feelings, for instance while the child might say I am on level 1, the mother felt he was at a higher level.

**Parent** *with my son, he used this thermometer Ok, and he is quite clear what number he is, sometimes I disagreed from outside [symptoms]. He said I am only one and I think he is 3 or 4, so I am not sure how well he is rating his anxiety” (Child 2).*

The reason behind why children are not telling parents their real anxiety level appears to be due to:

**Parent:** *if you asked [the child] which picture or number? Then you will begin to say why? And that they do not want to tell you, or sometimes they are not sure as they do not know” (Child 3).*

**Parent:** *they do not want to say they do not know why they are anxious a lot of the time” (Child 2).*

## ■ Reactive strategies (red)

The scope of these strategies was to deal with the child’s / young people’s high anxiety and to help children / young people to cope with their anxiety. These included distraction, having a little fun, quiet-time, and a comfort strategy (cuddling & reassuring). Distraction was reported as the most useful and most often used strategy. However, comfort strategies, have a little fun and quiet-time were reported the least used strategies by parents. It was indicated that have a little fun was not appropriate when the children are highly anxious, or agitated, as they couldn’t find fun at this moment. Children / young people were distracted by painting, physical exercise, feeding the birds or a favourite interest.

**Parent:** *“The most effective one with my son is extensive physical activities as distraction when he is very anxious before he can calm down at all so that would be first thing and then painting a model” (Child 2).*

**Parent:** *“Easily distracted by something in the garden, he is very interested. Instantly direct him, like the bird feeding area, he is usually interested to come and see of what is going on, oh look there is Robin attacking, you know, another bird coming to the garden! I think he forgot what he was doing. Just focus on that and that sort of thing I would do to distract him, bird feeding area. Have you tried your painting, try to go and get your paints out, because sometimes he won’t do this by himself, but if you tell him he says oh yes I will get my paint.....” (Child 4).*

**Parent:** *“Mostly distraction by playing his game on the computer games, because he likes that. It does work. Umm also he likes some time like he is very artistic and he likes building things, yeah just let him play his favourite game” (Child 3).*

**Parent:** *“He has a little model war hummer. It is like something for a teenage boy, little model but you paint, sort of fantasy buckles and he got some of skeletons and horses something like this. You need to concentrate really hard, and he found that really relaxing. That ‘s what he does, he used that for relaxing mostly if he is really anxious he then used this in the red and umber level (Child 2).*

**Parent:** *“Reading, he likes reading, because I normally read in many ways with my younger, and he will not miss it he always says wait for me, he loves it” (Child 4).*

**Parent:** *“Trying to reassure him, giving him a cuddle like that really tight he needs to feel secure. Something I only can do calm down do not say anything, it is too much to talk and hug. Just be silent, hug is enough” (Child 3).*

### **6.6.3. Evaluation of the programme**

The parents provided many useful insights of using the strategies, for example: this programme initiated to support parents to help their children and young people to cope and manage their anxiety. It is not surprising that children and young people started to use some of their strategies when they were feeling stressed or worried, in other words “self management”. Parents illustrated that:

**Parent...** *If he is very anxious he will go and do lots and lots of sit ups very very fast so he feels better. It goes from him any way” (Child 2).*

**Parent:** *“If he feels particularly anxious he uses hand exercisers in his coat pocket where no one can see him” (Child 4).*

They also raised issues about individual differences. While some children enjoyed listening to music as a relaxation technique, others hated music and preferred physical exercise. It is therefore important to indicate that implementing strategies were influenced by individual’s differences.

**Parent:** *“I ‘ve done some music [relaxation technique] with him but he does not want to do, he would prefer doing something strength, physical activities preferred. He likes something very fast you know. Listening to music, I do not think applies to him” (Child 2).*

On the other hand, another mother reported:

*"I set up time to music time, listening to relaxing music. This really helped"*  
(4).

In addition, parents indicated that this programme helped them to structure the family's life, and helped overcome some of the obstacles they faced. Parents described that any changes to their child's / young people's behaviour could be attributed to participation in the programme. They pointed to the changes of their child. In the following quotes, parents described how this programme impacted their child's life:

**Parent:** *"He is more able to cope [now] when we have something unordinary, i.e. visitors, holidays" (Child 4).*

**Parent:** *"Certainly, having structured what my son is doing, it is more structured in my mind now and my son's mind as well, rather than before".*  
(Child 3).

**Parent:** *"He is generally quite calm on a daily basis; it is only changes to routine which cause him anxiety now, particularly holidays and visitors. However, I found the strategies useful for tackling anxiety-producing situations when they did occur" (Child 2).*

**Parent:** *"She is happier, calmer, and enjoys herself" (Child 5).*

Furthermore, the parents reported their feedback in evaluation form in relation to the Calm Child Programme. Over the entire programme, parents reported that the information booklet was very good, and the information provided was very simple and practical to use. Regarding the time span of the programme, it was just right, not too long or too short. Moreover, parents had reported that the information provided in the booklet had met their expectations for helping the child manage their anxiety. In support of the GAS results, qualitative data indicated that the programme was successful in coping with children stresses. Parents have been advised to carry out some of these strategies in the future, particularly preventing strategies that aimed to prevent triggering anxiety (Green level), for example talking & explaining, regular physical activities, and timetable.

## **PartIFISMPV' VuJJIVPMV**

From Parents' Group discussion, parents reported some suggestions in terms of the Calm Child Programme. These suggestions are as follows:

- Timing of the supporting parents:

Parents found this programme useful in managing their children's and young people's anxiety. Interestingly, many parents indicated that they would like to have had this booklet when their child was younger when he/she was just diagnosed with autism, as they had to find their own ways to deal with the child's anxiety. One parent stated that:

**Parent:** *"I would love to have had this booklet when my son was first diagnosed with autism at age 4! I have generally had to find my own ways to deal with his anxiety" (Child 2).*

- Understanding more about the child and

autism Another parent indicated:

**Parent:** *"Understanding what are sensory that makes the child anxious, such as sound for example it helped. You may need to explain more about the factors which may trigger the anxiety, because we did not know that sound or noise cause the anxiety and crying for my son" (Child 5).*

- Have a little fun strategy

Some parents indicated that have a little fun strategy is not applicable with children when they are very anxious, as at this moment there is nothing fun. It was suggested that "have a little fun" strategy would be better to use when the child is a little bit anxious (could be included in the second facet of strategies amber level).

Parents' suggestions will be considered in improving the Calm Child Programme. The refinements are reported in the discussion chapter. The Calm Child Programme is illustrated in Appendix - XII).

## **6.7. CONCLUSION**

The focus of this study was implementing and evaluating the Calm Child Programme with parents of children and young people with LD and autism. This programme was found to be useful for children and young people with LD and autism in managing anxiety. The findings indicated a reduction in the child's / young people's anxiety after its use by parents. There was a statistically significant difference in children's and young people's anxiety between pre- and post-test using the Wilcoxon test. The results showed that children's / young people's anxiety scores on the GAS-ID after the programme were ( $M=16.43$ ;  $SD=3.599$ ) lower than the anxiety scores before the programme ( $M = 27.29$ ;  $SD = 5.282$ );  $Z = 2.371$ ,  $p < .05$ . In addition, the group discussions' results emphasised the effectiveness of the consensus strategies of managing the child's / young people's anxiety. The most effective strategies were talking & explaining, physical activities, and distraction. Overall, parents reported benefits of implementing the strategies in managing their child's / young people's anxiety.

The upcoming chapter will discuss the findings of this research, and its implication for further research.

## ***CHAPTER 7: DISCUSSION***

### **7.1. INTRODUCTION**

The purpose of this research was to explore the prevalence of anxiety and to develop and implement a Calm Child Programme, a consensus of management strategies for parents of children and young people with LD and autism to help their children and young people manage the anxiety. To address this aim, three interlinked studies were conducted in this research. Therefore, there were four objectives:

- (1) To screen for mental health problems and anxiety amongst children and young people with LD and autism, this was dealt with by conducting a screening study;
- (2) To identify everyday strategies that parents and teachers use to manage anxiety in children and young people with LD and autism;
- (3) To develop a programme of management strategies in managing anxiety for young people with LD and autism incorporating the views of parents and health professionals; the second and the third aim were dealt with the second study developing the parental programme “Calm Child Programme”.
- (4) To implement and evaluate the programme of anxiety management strategies with a small group of parents of children and young people with LD and autism. This was dealt with by conducting the implementing the “Calm Child Programme” study.

This discussion is organised in three sections presenting the three studies in sequence. Each section begins with the aim, followed by a brief summary of the findings which have been presented in the previous chapters. Following

this, key issues from this research addressing anxiety in children and young people and involving parents in interventions will be addressed.

Developing a programme for parents for managing a child's / young people's anxiety is important for a number of reasons. Parents have been considered as the main source of support to their children / young people throughout their lifetime (Heiman and Berger 2008; Buckley 2002). Additionally, parents usually spend more time with their children and young people, in various settings and more diverse situations (Matson et al. 2009). Furthermore, involving parents in the intervention is useful for strengthening the family's capability to meet the needs of their child / young people (Wang 2006). Previous research on children and young people with LD and autism highlighted that parents' involvement contributed to the success of the intervention for their children and young people (e.g. Sofronoff and Attwood 2003; Reavon and Hepburn 2003). Indeed, the current research has clearly highlighted that developing and structuring a programme with parents would be helpful in managing the child's and young people's anxiety. Consequently, this research has focused on supporting parents in the intervention for anxiety by developing and implementing the Calm Child Programme of management strategies for anxiety.

This research aimed to empower parents via two different directions: first, developing the Calm Child Programme of parental management strategies based on the parents' experiences. The management strategies were identified by parents themselves through the interviews. Second, providing parents with the Calm Child Programme provides parents with useful strategies, and supports them, so that parents are empowered to help their children and young people in managing the anxiety.

This study contributes to the growing body of research on anxiety management in children and young people with LD and autism and supporting parents because it explored and developed a specific programme of parental management strategies for this population. It was clear that the

developed “Calm Child Programme” of anxiety management strategies had an effect on the child’s and young people’s anxiety. Parents reported the usefulness of the use of this programme. A more detailed summary of the findings is presented in Table 7.1 below. The following sections will present a more detailed discussion on how these findings significantly add to our growing knowledge of autism.

**Table 7.1. Summary of Research Findings.**

Study 1	Study 2	Study 3
<ul style="list-style-type: none"> <li>• Prevalence of mental health problems was 61.3% in children and young people with LD and autism, with a mean age 12.3 years.</li> <li>• Prevalence for anxiety on Glasgow anxiety scale was 32.6%.</li> <li>• 92% of those who scored positive for anxiety reported suffering from mental health problems on Reiss Scale.</li> <li>• There was no significant statistical correlation between age and GAS-ID anxiety.</li> <li>• There was a significant positive correlation at 0.05 between worries (GAS- ID subscale) and age (<math>r = .337</math>, <math>p = .018</math>).</li> </ul>	<ul style="list-style-type: none"> <li>• Sixteen different strategies were identified by parents, carers and teachers.</li> <li>• Delphi technique with an expert panel of health professionals reported the 10 most appropriate strategies for anxiety.</li> <li>• A useful programme of anxiety management strategies “calm child programme” was developed based on parents’, carers’ and teachers’ experiences and the expert opinion of the professionals.</li> </ul>	<ul style="list-style-type: none"> <li>• The Calm Child Programme was implemented and evaluated with seven parents</li> <li>• The results indicated a reduction in the child’s and young people’s anxiety after its use by parents.</li> <li>• The results showed that anxiety scores on GAS-ID post- test were (<math>M = 16.43</math>; <math>SD = 3.599</math>) significantly lower than the anxiety scores pre- test (<math>M = 27.29</math>; <math>SD = 5.282</math>); <math>Z = -2.371</math>, <math>p &lt; .05</math>.</li> <li>• The most effective strategies were distraction, physical activities, and talking &amp; explaining.</li> </ul>

## **7.2. STUDY 1: SCREENING FOR ANXIETY**

**Aim 1:** To screen for mental health and anxiety amongst children and young people with LD and autism.

The primary aim of the screening was to identify anxiety in children and young people with LD and autism and to obtain participants for the following study. For this purpose the Reiss Scale and GAS-ID were used to identify anxiety in children and young people. Different multiple assessment was applied in this study using two different scales to assess anxiety. An interesting result was that all participants who scored positive for anxiety on Reiss, also scored positive on GAS-ID, excluding the five cases who failed to complete GAS-ID. The results of the screening for anxiety of Reiss subscale concurred with the results from the GAS-ID scale, which indicated the compatibility of the two scales.

The discussion for this study includes: prevalence of mental health, the prevalence of anxiety, factors influencing high anxiety and lastly the need for assessment and management.

### **7.2.1. Prevalence of mental health in children and young people with learning disabilities and autism**

This study screened for mental health problems and anxiety in children and young people with LD and autism, aged 5 to 18 years (mean age = 12.25). The results of the screening study indicated that children and young people with LD and autism showed high prevalence rates of mental health problems (61.3% (92/150) on the Reiss Scale). Little research has been conducted on the prevalence of mental health problems for people diagnosed with comorbid LD and autism. It is important to note that there is no published research concerning mental health problems conducted on children and young people with mild to moderate LD and autism. Therefore the current

findings will be discussed in light of the limited research available which has assessed mental health problems in people with comorbid LD and autism. In addition to other research concerning mental health in population of children with LD but without autism, as well as research concerned children and young people with ASD will be discussed.

- ***Comparing with previous studies of mental health in people with comorbid LD and ASD***

The current findings were consistent with those of earlier studies suggesting that adolescents and adults with LD and ASD show higher rates of mental health problems. There are only two published studies that have focused on mental health problems for young people and adults with severe LD and varying severities of autism compared with another group of people with LD, those without autism (Bradley et al. 2004; Hill and Furniss 2006). These studies consistently indicated that people with LD and autism have higher rates of mental health problems than people with comparable levels of LD without autism.

- ***Comparing with previous studies of mental health in children with LD:***

The current evidence of this research is comparable with studies concerning the prevalence of mental health problems in children with LD (without autism) The prevalence rate of 61.3% is thus consistent with those of recent studies in suggesting that young people with LD showed high prevalence of mental health problems. This is supported by Kaptein et al. (2007) who showed a prevalence of 60.9%; and the study by Smiley (2005) which indicates that the rates ranged from 30 to 50%. On a general level, the prevalence of mental health problems in adults with LD ranged from 10 and 80% (Brothwick-Duffy 1994). The findings of the present research reported higher prevalence rates (61.3%) of mental health problems in children and young people with LD and

autism than prevalence rates of mental health problems among children with LD but without autism (36%), as identified by Emerson and Hatton (2007).

- ***Comparing with previous studies of mental health in people with autism:***

The prevalence rates of mental health problems of this research were higher than the rates reported in the literature for children with autism (30 -33%) as identified by Green et al. (2005) and Hartly and McCoy (2008). The literature has recognised that children and young people with autism have high level of mental health problems (Brereton et al. 2006).

Overall, it could be concluded that the current findings of prevalence rates of mental health problems (61.3%) are consistent with previous research concerning comorbid populations of adults and young people with LD and autism, indicating that they have high prevalence rates of mental health problems.

### **7.2.2. Prevalence of anxiety in children and young people with learning disabilities and autism**

The findings of the screening study indicated that the prevalence of anxiety was 36% using the Reiss Scale, and 32.6% on the GAS-ID for children and young people with LD and autism. Although previous research has tended to focus on anxiety either in people with LD or people with autism, rather less attention has been paid to children and young people diagnosed with comorbid LD and autism. The current results contribute to our knowledge about the prevalence of anxiety in children and young people with LD and autism.

The results from the screening study in this research showed that the majority of children and young people with anxiety had mental health problems. The findings of the Reiss Scale illustrate that over 92% of children

and adolescents who suffered from anxiety had a mental health problem. Those consisted around 33.3% of the overall sample, as diagnosed by the Reiss Scale. In addition, anxiety coexisted with other mental health problems. The most commonly associated problems were anger, social withdrawal and psychosis, as indicated in the results of this PhD research.

Another point is that anxiety is one of the most prevalent mental health problems in people with LD and autism. The present findings are consistent with the literature which highlight that anxiety is among the most prevalent mental health problems in people with LD and autism (Bradley et al. 2004; Hill and Furniss 2006; Brereton et al. 2006; Kanne et al. 2009; Emerson and Hatton 2007). The study of Bradley et al. (2004) illustrated that adolescents and young adults with severe LD and autism have higher rates of anxiety (42%) compared to a group with LD and without autism on the DASH-II subscale. Brereton et al. (2006) also reported that young people with autism were found to suffer from significantly higher levels of anxiety than young people with LD. This study indicated that the symptoms of anxious behaviour included fear of separation from familiar people, resistance to change, crying easily over small upsets, tenseness, shyness and irritability (Brereton et al. 2006).

It is important to indicate that there is no published research that focuses on the prevalence of anxiety in the population of children and young people with mild to moderate LD and autism. Therefore, the discussion of current findings are comparable to previous research that has assessed anxiety in either children with LD but without autism, or research discussing anxiety in children, adolescents and adults with autism.

#### ***Comparing with previous studies of anxiety in people with LD***

The current finding of the prevalence of anxiety in children and young people with LD & autism, as identified in this research, is 32.6%, which is higher than previous prevalence rates of anxiety in children with LD. For example,

Emerson (2003) identified anxiety in 8.7% of children with LD aged 5 to 15 years; Dekker and Koot (2003) identified anxiety rates of 21.9% in people with LD aged between 7 and 20 years.

### ***Comparing with previous studies of anxiety in people with autism***

The current findings of prevalence rates of anxiety 32.6% (n=150) were higher than Kim et al. (2001) who reported a rate of 13.6% from a sample of 59 children with autism. However, these findings were lower than other studies which reports prevalence rates for anxiety in children and young people with autism. For example, Simonoff et al. (2008) found that within a sample of 112 young people with autism, 41% of young people presented anxiety. Sukhodolsky et al. (2008) reported that 43% of children with autistic disorders within a sample of 171 met the criteria for at least one anxiety disorders, and Gillott et al. (2001) found that within a sample of 15 children with high functioning autism, 47% had anxiety. Furthermore, Muris et al. (1998) reported that 84% of a sample of 44 children and young people with autism met the DSM-IV criteria for at least one anxiety disorder. It appears that the reason for this variation in these prevalence rates is due to the use of different instruments and assessment approaches to assess anxiety, and the difference in the number of people who were assessed. In addition, the characteristics of the individuals being evaluated and severity of autism were different (e.g. autism disorders, high functioning autism, and LD level).

In terms of the age and anxiety trends, the results in the current study indicated that the anxiety mean scores for children were similar to those of young people. Although, there was no significant correlation found between age and anxiety, a significant positive correlation was found between worries on the GAS-ID and age. Another potential concern of the findings is that up to two thirds (66.6%) of those children and young people who tested positive for anxiety on the Reiss Scale were aged between 9 to 15 years. This finding supports other research which has reported increased symptoms of anxiety in young people at this age (Weisbrot et al. 2005).

An explanation for this finding is that anxiety is more likely increased in the transition age, from childhood to becoming a teenager. Growing up would be considered a difficult and stressful period for many young people and adolescents and may be even more stressful for young people with LD who are not fully aware of the process of change and are faced with making choices about future wishes and aspirations (Graham 1991; DOH 2001; Raghavan & Pawson 2008). The transition from childhood to adolescence is a stage when young people are most vulnerable to develop mental health problems (FPLD 2005). It is a period of enormous change as young people begin to have adult capacity, although their behaviour may occasionally be more childlike than adult (Flynn and Russell 2005). For example, they are more likely to be worried about bodily appearance, leaving home to live independently, and also worrying about the future (Graham 1991). Thus, it is expected for adolescents to have more worries. Transition from childhood to adulthood is a challenging time for children with autism who have difficulty adjusting to changes in their environments (Loveland and Tunali-kotoski 1997), and brings several changes in the lives of young people with learning disabilities, especially loss of their friends and social networks (Raghavan & Pawson 2008). This resulted in young people with LD being at more risk of developing mental health problems (Raghavan & Pawson 2008). Many problems identified by parents and young people were to do with inadequate system of support, and difficulty on transitions in particular when they confused about their future (Williams and Heslop 2005). Furthermore, it is also possible that as children grow older they are better able to express their emotions, their parents become better observers of anxiety, or these symptoms become more prominent in the home (Weisbrot et al. 2005).

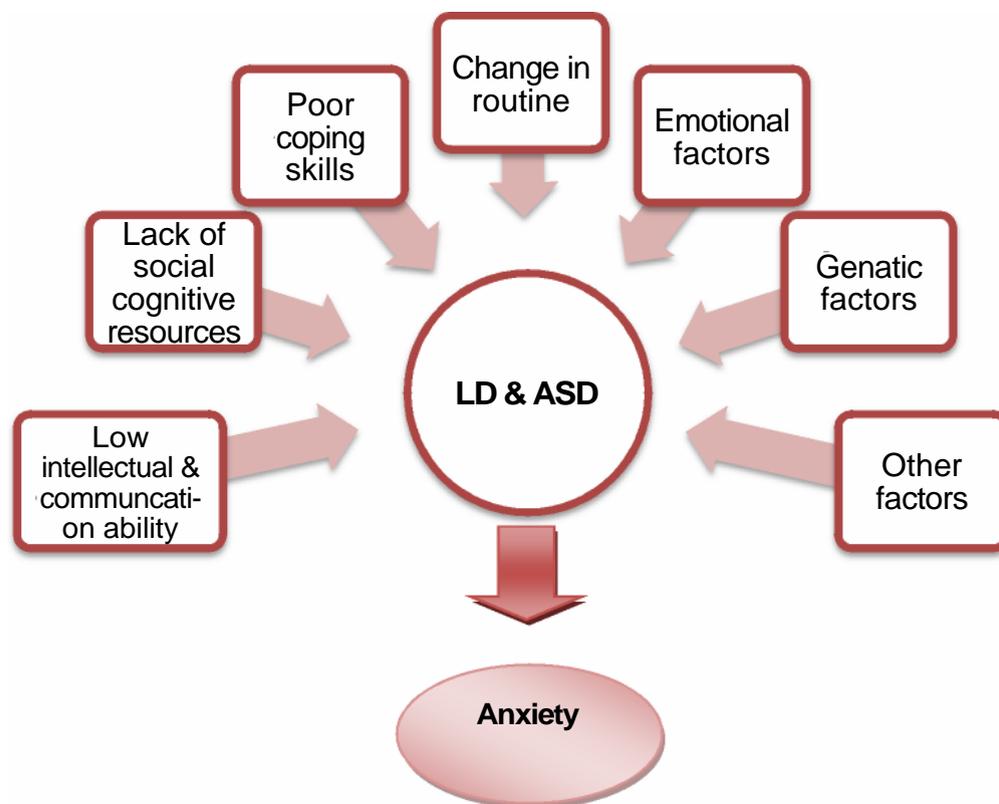
Overall, these findings support conclusions that the prevalence of anxiety in children with autism is higher than children without autism. Research addressing anxiety in children with LD and autism suggests that the high prevalence might be associated with additional variables that put people with learning disabilities at increased risk for developing anxiety (Raghavan 1998). This is because children and young people with LD are often exposed

to enormous stress (Melfsen et al. 2006). For example poor social skills could contribute to social anxiety (Bellini 2004). Other factors likely to increase the prevalence of anxiety include a lifetime of adversity, inadequate social support, and poor coping skills (Cooray and Bakala 2005). Also, a lack of social and cognitive resources to cope with adulthood is thought to contribute to this vulnerability to social and emotional problems (Wilson 2004). The present findings support that those children with LD and autism experience a high prevalence rate of anxiety. It is clear therefore that children and young people with LD and autism are more vulnerable to anxiety. Collectively, the following factors and impairments were found in the literature to complicate anxiety in this group of children and young people with LD and autism.

### **7.2.3. Factors influencing high prevalence of anxiety**

The occurrence of a high prevalence of anxiety in this group as reported from this research has been suggested to occur as a result of the interplay between autistic and disability features, LD, genetic and contextual factors, as shown in Figure 7 (a). The possible explanation for this high anxiety can be attributed to:

**Figure 7 (a): Risk factors for anxiety in people with LD and autism**



### **I. Autism and disability features**

It is recognised that emotional problems occur frequently in children and young people with autism as consequences of the features that define autism (Leyfer et al. 2006) particularly for higher functioning individuals who are more aware of their difficulties and challenges. The vulnerability to anxiety has been predicted due to the features of autism and disability. For instance, low intellectual and communication ability, lack of social and cognitive resources and poor coping skills might affect the increased prevalence rates of anxiety disorders (Cooray and Bakala 2005; Wilson 2004; Deudney and Shah 2004; Groden et al. 2001; Wilson et al. 2005).

Low intellectual ability and poor cognitive skills are more likely to lead to poor self esteem and, in turn, an increased vulnerability to anxiety (Henry and Crabbe 2002). Moreover, the lack of communication skills results in greater difficulties in discussing or dismissing fears, resulting in over-generalisation (Smiley 2005). Likewise, poor coping skills are an associated factor, as unfamiliar problem-solving tasks for children with LD induce more anxiety (Henry and Crabbe 2002).

Due to lack of communication skills and cognitive deficits in children with autism (Brereton & Tong 2002), they often have difficulty understanding what is expected of them and what is happening around them; and as a result anxiety and agitation are understandable reactions to this constant uncertainty (Society for The Autistically Handicapped: SFTAH 2006). Individuals with autism are often resistant to change, and as a consequence anxiety can also result from any change in routine, over-stimulating environments, frequent changes and unpredictable changes (Brereton & Tong 2002; FPLD 2002; Society for The Autistically Handicapped 2006). Furthermore, co-morbidity specifically of LD and autism may also make the young people with LD more susceptible to anxiety (FPLD 2002; Seidel et al. 2007).

## **II. Emotional factors**

Individuals with LD and autism may not be able to describe or understand what is happening to them and communicate their emotions (Sullivan et al. 2007; Wilson et al. 2005). Children with LD have difficulty expressing their emotions and feelings (Li & Morris 2006). Furthermore, due to psychological factors such as a reduced capacity for coping with stressful circumstances, poor memory and poor problem-solving and planning skills, people with LD may be at greater risk of developing mental health problems (Van den Hout et al. 2000). Deficits associated with autism, such as difficulty in understanding emotions and interpersonal relations, along with misinterpretation of social cues, may lead to anxiety.

### **III. Sensory**

Sensory integration affects a significant number of individuals with autism (Rogers, Hepburn and Wehner 2003). They often experience forms of sensory sensitivity, either hyper-sensitive or hypo-sensitive (NAS 2007; Aron & Aron 1997). Hyper-sensitive refers to taste and smells, noise (i.e. baby crying, vacuum cleaner, or ringing telephone), and even being sensitive to any touch as they frequently find touch of any kind distressing and threatening (Roger et al. 2003; Attwood 1998). This can impact greatly on their behaviour. Research has outlined a neurological basis for extreme sensitivities to sound, touch, and / or textures among individuals with autism (Grandin 1995; Trepagnier 1998) that may explain the need for sameness as an attempt to self-regulate one's behaviour in response to overstimulation of the senses.

Given this evidence it might explain the vulnerability of children with autism to any sound, noise, or even being cuddled by someone, which can lead to anxiety. Overall, research shows that sensory processing is related to autism symptoms and anxiety. In the present research, parents reported that around 35% of their children were anxious around noises, for example baby crying.

### **IV. Brain mechanism and Genetic factors**

It is suggested that genetic factors contributed to anxiety in people with LD and certain behavioural phenotypes. For example: fragile-X syndrome is associated with social anxiety; Rubinstein-Taybi and Prader-Willi syndromes with obsessive-compulsive disorder (Levitas and Reid 1998); and phenylketonuria and Williams syndromes with generalised anxiety (Smiley 2005; Einfeld et al. 2003). It has been suggested that the amygdala may contribute to comorbid anxiety in children with autism (Amaral and Corbett 2003; Juranek et al. 2006). It appears that the amygdala contributes to the abnormal fears in children with autism and increased anxiety (Amaral and Corbett 2003).

## **V. Contextual factors**

Contextual factors have been found to play a role generally in children's anxiety. For example, parental behaviour is one such mechanism proposed to be associated with the stability of behavioural inhibition in children (Donovan & Spence 2000). Some parents anticipate their child's anxiety. This is especially true when parents tend to be overprotective to their children (Van der Bruggen, Stams, and Bogels 2008; Rapee 2008). Parental anxiety also represents documented risks for child anxiety (Klien 2009). In addition, some of this anxiety can result from frequent confrontations with an environment that is unpredictable and overwhelming (SFTAH: Society For The Autistically Handicapped 2006). Other risk factors may be involved in developing anxiety, such as traumatic, negative, and stressful life events representing risk factors for childhood anxiety problems (Ray 1994; Donovan & Spence 2000; McFarlane 1987).

In brief, all the above factors suggest that people with LD and autism are at a high risk of developing anxiety. The co-morbidity of autism and LD results in increased vulnerability to factors which may trigger anxiety. There is no literature focused on the anxiety in children and young people with mild to moderate LD and autism. The contribution of this research provides insight into the high prevalence rate of anxiety in this population. This anxiety may cause significant clinical impairment and additional burden of illness on children and young people with LD and autism and their families. This highlights the need for assessment and management strategies for anxiety.

### **7.2.4. The importance of assessing and recognizing anxiety**

Given the high prevalence of anxiety in children and young people with LD and autism found in this research, and in the discussed literature, it is clearly important to have reliable and valid ways of assessing anxiety. The Glasgow anxiety scale (GAS-ID) covered a range of symptoms for anxiety, such as worries, fears and physiological symptoms which are likely to be targeted for

psychosocial intervention. This is a good measure that can describe and quantify anxiety symptoms (Mindham and Epsie 2003). However, no studies to date appear to have looked specifically at anxiety in children and young people with comorbid LD and autism. Prevalence studies are required to determine the prevalence rates for anxiety in this group. Identifying and accurately assessing potential mental health problems in children with learning disabilities and autism is a necessary first step in an effort to promote good mental health. It is suggested that early detection of anxiety symptoms by parents is more likely to prevent reactions which might lead to full-blown anxiety (Raghavan 1998). As with many conditions, early identification is important in order to initiate intervention and reduce the probability of long-term or secondary problems.

This research highlights the important theme of anxiety in children and young people with LD and autism. This research addresses the prevalence of the anxiety filling gap in existing literature, where the prevalence rates of anxiety in children and young people with LD and autism needs to identify. During the conceptualization and design this research there was no empirical literature that had investigated the assessment and intervention for anxiety in children and young people with LD and autism. Furthermore, it is important to consider two particular papers (White et al. 2009; MacNeil et al. 2009) with relevance to the present research have been published recently. MacNeil et al. (2009) call for further research to investigate the prevalence and methods to assess anxiety in low functioning youth with ASD. White et al. (2009) in a review of the literature on anxiety in children and adolescents with ASD claims that there is no psychosocial intervention research that it is developed for anxiety in children with autism who are also having learning disabilities. However, studies have been conducted with higher functioning children with ASD. These reviews emphasised that there are no published studies concerning the assessment of anxiety and the implementation of intervention programmes for anxiety that have been developed specifically for young people with autism.

The focus of this research was to assess anxiety and supporting parents to manage the children's and young people's anxiety. The importance of supporting parents in managing children's / young people's anxiety is based on the premise that parents are the child's most important resource and they have a vital role to play in providing the help that their children / young people needs. Research has documented the importance of involving parents in the intervention process (Diggle et al. 2008; Ozonoff and Cathcart 1998). Additionally, parents of children and young people with autism possess an experience-based or lived understanding of their children. Hence, they may be considered experts on their children. Furthermore, providing parents with useful management strategies could help to strengthen the family's capacities to meet the needs of the child (Wang 2006); enhance parents confidence (Plant and Sanders 2007); and relive parental stress (Tehee et al. 2009; White and Hastings 2004).

The following section discusses this second study which developed a parental programme of anxiety management strategies from parents', carers' and teachers' experiences and health professionals' views.

### **7.3. STUDY 2: DEVELOPING CALM CHILD PROGRAMME**

***Aim (2):*** To identify everyday strategies that parents, carers and teachers use to manage anxiety in children and young people with LD and autism.

***Aim (3):*** To develop a parental programme of management strategies in managing anxiety for young people with LD and autism incorporating the views of parents and health professionals.

Thirty four parents, carers and teachers were interviewed to illicit their experiences of management strategies in day-to-day life to manage the child's / young people's anxiety. Findings from parents', carers' and teachers' interviews revealed important issues regarding anxiety in those

children and

young people. Parents reported that the children and young people experienced some antecedents of anxiety. Parents' experiences illustrated that these parents use different strategies with different children / young people at different ages for anxiety management.

This section discusses themes derived from the interviews with parents, carers and teachers. Three main themes were found from the interviews: 1) Antecedents of anxiety; 2) Management strategies and 3) Aims of the management strategies.

### **7.3.1. Theme 1: Antecedents of Anxiety**

The results from the parents', carers' and teachers' interviews indicated the factors that can lead to the feeling of anxiety in children and young people with LD and autism. In interviews, participants were asked about factors that could contribute to children's anxiety. They reported that children and young people with LD and autism in this study experienced anxiety in response to various factors "antecedents" or anxiety provoking events. These factors included change in daily routine, meeting new people, unexpected / new situations, noise, babies crying, dogs and cats, dentists, crowded places, the dark, worries about family and the future. The findings of this research were similar to those in typically developing children in the following antecedent: fears of dogs and cats, the dark, dentists, and worries about families and the future (Graham 1991). Despite some similarities, anxiety in children and young people with LD and autism differs in important ways from children without disabilities. These included: changes in routine, noise and babies crying, and meeting new people. A likely explanation for these differences is due to unique features related to children with autism. For example, children with autism have sensory integration difficulties. These sensory integration difficulties of children with autism could explain the anxiety to noises and babies crying (Grandin 1995; Trepagnier 1998). As discussed in the

literature, children with autism are constantly resistant to change in any routine (Brereton & Tong 2002; FPLD 2002), so an interruption to daily routines may lead to significant anxiety and distress. Additionally, the general nature of triggers was similar for all children and young people; however, the specific events that triggered anxiety in the children and young people varied and reflected their individual differences. Finally, children and young people with autism can become anxious about strangers. As discussed earlier in this chapter, these findings concur with other literature indicating that anxiety in children with autism was influenced by the presence of impairment associated with autism (Rogers, Hepburn and Wehner 2003).

The present findings and previous research support the claim that the presence of autism and LD can heighten the occurrence and intensity of anxiety. Impairments associated with autism were indicated among all participants of this study, the factors that influence the presence of anxiety have been discussed throughout this chapter. Discussing the problem and its causes with parents was important to identify management strategies. Understanding the trigger factors and characteristics of individuals with LD and autism is invaluable for designing a viable programme of management strategies and intervention.

### **7.3.2. Theme 2: Strategies used by parents, carers and teachers**

This study addressed parents' carers' and teachers' experiences about anxiety management strategies for children and young people. A range of management strategies for anxiety were identified by parents, carers and teachers. These included cuddling, reassuring, talking and explaining, stop thinking, grading anxiety, visual schedule / timetable, relaxation, physical activities, quiet-out, distraction, have a little fun, rewarding, flooding, remove physically from the situation, massage, and reinforcing.

The results indicated that parents, carers and teachers utilised a variety of

strategies to manage children's and young people's anxiety. The results suggested that similar strategies were used with children and young people. However, these approaches were influenced by the individual's age as well as individual's differences. For instance, the findings indicated that talking and explaining were used more with young people than children. As children grow older they are better able to understand, and therefore parents were able to talk and explain more issues with their young people. Many participants reported that the use of a timetable was an effective strategy. Parents used timetables in different ways with different age groups. Whereas children used visual timetables, written timetables were used with young people. It is important to note that young people are able to read and understand the timetable when it's written. However, this is probably dependent on the severity of autism and LD. Furthermore, the strategy "have a little fun" was found to be used less often with young people than with children. Encouraging children to have fun might be easier rather than adolescents. Parents engaged their children to have fun through their favourite sweets, a lovely game, some activities, and watching their favourite movies.

Participants' perceptions were that relaxation techniques were beneficial in lowering the anxiety level. Participants reported that children and young people with LD and autism also utilized several relaxation techniques (e.g. listening to music, deep breathing) to reduce their anxiety. The choice of relaxation method depended very much on the age of the individual and the situation at school or home. Parents indicated that young children responded to watching their favourite movies, playing with their favourite toy or a game as a relaxation, while young people and adolescents preferred to listen to calming music. Quiet time was another form of relaxation used to reduce children's anxiety symptoms. This is related to previous research in implementing parents' programmes using quiet-time (time-out) with children with LD (Plant and Sanders 2007; Quinn et al. 2007).

With regard to the individual's differences, all participants reported using distraction techniques or taking actions that replaced a concerning thought of anxiety with one that was more calming (i.e. feeding the birds, painting, watching a favourite DVD). Participants reported that they used distraction techniques effectively to manage anxiety symptoms with their children. Distractions varied between participants, and no one distraction technique was used by all. Rather, the form of distraction selected by participants was individual and based on personal areas of child interest. Thus the children's differences were found to affect the nature of these strategies.

There is some research evidence concerning the efficacy of some of these management strategies for a range of mental health problems including anxiety for young people with autism or research in children and young people with LD, such as CBT. In this research, participants' insights into the effectiveness of relaxation are related to previous findings that relaxation can reduce anxiety (Green et al. 2006; Bishop 2004; Lindsay and Baty 1986; Lindsay et al. 1989; Morrison and Lindsay 1997; Chalfant et al. 2007). In an internet survey to identify strategies used by parents of children with autism, Green et al. (2006) reported that visual schedule is a familiar treatment strategy used with children with autism, reporting by 43.2% of parents of children with autism (Green et al. 2006).

Participants in this study indicated that physical exercise (e.g. walking, running, using trampoline) was useful to manage anxiety. Participants' insights into the benefits of exercise validate previous literature that physical exercise can positively influence anxiety in young people with LD and autism (Attwood 1998). This also indicated that it can positively influence both appropriate and inappropriate behaviour in individuals with autism (Boon Hong 2002 a,b). Furthermore, physical activities have been used for different disorders with children with autism (Chien-Yu Pan & Frey 2006; Chiu Mei 2003; Elliott et al. 1994; Kern et al. 1984).

Literature has indicated that reinforcement strategy is used on the treatment of some forms anxiety such as phobic avoidance in children with autism (Hagopian and Jennett 2008). Distraction appears to be an effective strategy in reducing anxiety in people with LD. Children were distracted to play with their favourite toy or painting. It is helpful if children are encouraged to draw or play with small toys. This is consistent with previous findings reporting that parents can use distractions to manage behaviour in children with developmental disabilities (Plant & Sanders 2007).

Overall, present findings suggested that parents, carers and teachers were successful in utilizing several effective management strategies with children and young people with LD and autism. Furthermore, the best management was achieved by using a combination of two or more techniques. These management strategies were found to bring positive coping outcomes.

The analysis of the management strategies collated from study 2 revealed three different categories of strategy type: emotional, cognitive, and behavioural approaches. This is shown in the following examples:

### ***I. Emotional coping strategies***

This involved two comfort approaches, cuddling and reassurance. The comfort approach appears to be a very common approach used by parents. The comfort approach includes physical affection (e.g. cuddling) or closeness or telling the child that “everything will be all right” or also “there is nothing to be afraid of”, which is reassurance (Rapee et al. 2008). Participants utilized these comfort strategies in order to reassure children when they had fears or worries.

### ***II. Cognitive coping strategies***

This is focused on the principle that certain ways of thinking can trigger, or 'fuel' anxiety. The core principle of cognitive strategies may require

modification to meet the abilities of the individuals with LD. Cooray and Bakala (2005; PP. 359) state “evidence relating to the long-term outcome of these interventions is unavailable, although they are likely to be beneficial”.

## ■ ***Behavioural coping strategies***

This aimed to change any behaviour that was harmful or not helpful. Various techniques were used, for example: relaxation techniques; have a little fun; and quiet - time. Behavioural interventions appear to be effective in the management of specific behaviour problems which interfere with learning processes, such as aggressive outbursts (Clements 1987), and anxiety management training (e.g. Lindsay et al. 1989). As discussed in the literature chapter, the literature supports this conclusion that relaxation as a behavioural approach has been used successfully in reducing anxiety and improving cognitive performance amongst people with mild, moderate and severe LD (Lindsay, Baty, and Michie 1989; Morrison & Lindsay 1997).

The analyses indicate the emergence of using three types of coping strategies (emotional, behavioural and cognitive). All the participants described using comprehensive strategies including a variety of each type to deal with the child's / young people's anxiety. Participants cited using at least one of these types (emotional, cognitive and behavioural). It is important to highlight that the combination of different approaches in this study was similar to the content of the Cognitive Behaviour Therapy (CBT) programme which is applied in previous research concerning anxiety in children with Asperger's syndrome and autism (e.g. Reaven and Hepburn 2003; Chalfant et al. 2007). Participants of this research relied on various cognitive and behavioural strategies to help children manage and cope with anxiety. This finding is consistent with literature on the CBT treatment for OCD in children with Asperger's syndrome (Reaven and Hepburn 2003), and with the work of Chalfant et al. (2007), indicating that behaviour strategies such as relaxation were a major part of the CBT intervention programme to manage anxiety in children with autism. In addition, the cognitive component comprised of around 50% of the sessions of CBT programme for treating anxiety in children with high function autism (Chalfant et al. 2007).

Hagopian and Jennett (2008) have illustrated the idea that behavioural strategies (i.e. prompting, modelling, response prevention or the use of distracting stimuli, graduated exposure and reinforcement) are the most common type of intervention for anxiety in children with LD and ASD. Behavioural approaches may in fact be the "prominent approach" in intervention in children with learning disabilities and autism. The current findings support this possibility, as participants relied on behavioural strategies more than cognitive and emotional types of strategies to manage the child's anxiety.

### **7.3.3. Theme 3: management strategies**

For parents in the present research, the tendency to select management strategies was influenced by the intensity of anxiety experienced. Analysis of the range of strategies presented by parents, carers and teachers identified two categories of strategy. These included: proactive and reactive strategies. These strategies were analysed according to the intensity of anxiety. For example, parents suggested the use of time-table, talking and explaining in advance, and that appeared to be proactive approach to prevent developing the anxiety. Parents were more likely to engage the child in strategies such as distraction, relaxation, and quiet-out, each reactive strategy, if the anxiety was high (severe).

### **7.3.4. The need for a parental programme of management strategies**

Many parents raising children with disabilities find positive and negative aspects in the face of this great challenge. Although some of these parents often identify many positive strategies to help their son / daughter to cope with anxiety, others find it difficult to face this challenge and they experience difficulties in supporting their children, as discussed in the literature chapter. Those parents would benefit from more help and support particularly in the

early years of their children's lives when they often feel most vulnerable (Buckley 2002).

Although there has been much attention focused on the psychosocial intervention (e.g. CBT) for anxiety in people with LD and in people with autism, either separately or co-morbidly, very little has been published about the types of management strategies used by parents, carers and teachers for anxiety in these populations. Particularly, very little is known about the usefulness of these management strategies for parents with children with LD and autism. In this context, professional and appropriate support for parents to practice these management strategies is an important aspect that would help children to manage anxiety. It is suggested that there is an urgent need for an appropriate programme of intervention to help prevent and overcome mental health problems in this group (FPLD 2005). Thus, the third aim of this research was to develop a programme of management strategies from parents' experiences (as identified from the above study of this research), as well as health professionals' views. The aim of this programme is to provide parents and carers with a better understanding of management issues in anxiety and with recommendations for appropriate strategies for children with LD and autism.

#### **7.3.5. Calm Child Programme**

A parental programme of consensus management strategies for anxiety was developed using the Delphi technique. Group meetings were convened with a number of professionals working with children and young people with LD and mental health needs from CAMHs. This involved a discussion with the expert panel of health professionals regarding the strategies identified by parents, carers and teachers. This discussion helped to identify the most useful and appropriate strategies. The aim of this programme was to provide parents with recommendations for an appropriate programme of management strategies for anxiety. It was important to develop a consensus

with health professionals. Because of health professionals working in CAMHs are guided by evidence-based practice. This evidence-based practice is often based on expert opinion, clinical experience, service users and from contemporary literature (Brownrigg 2009).

### ***Developing the Calm Child Programme***

Sixteen different management strategies for anxiety were identified by parents, carers and teachers. The expert panel discussion had achieved agreement for most of these strategies. These included 10 useful strategies approved by the expert panel of the health professionals as follows: talking and explaining, physical activities, visual schedule / timetable, relaxation techniques, grading anxiety, distraction, have a little fun, reassurance, cuddling and quiet-out.

On the other hand, six strategies were eliminated, these included: massage, flooding, remove physically from the situation, reinforcement, stop thinking and rewarding, as illustrated in chapter 5, table 5.8. The first reason why some of these strategies were eliminated was that these were not appropriate for children with autism. For instance, Massage was eliminated because children with autism often have sensory sensitivity; children with autism have been reported to be opposed to physical contact (as discussed earlier in this chapter). Also, stop thinking appeared to be not appropriate for those children with LD and autism due to lack of cognitive abilities. The second reason was that some strategies were not practical for parents. "Remove physically from the situation" was found difficult to apply to some fears and worries, for example if the child was on a flight, parents would not be able to remove him physically from the aeroplane. The reinforcement strategy had also been eliminated, as that is more likely to enhance the child's anxiety. In addition, these eliminated strategies were the less common approaches and rarely used by parents, carers and teachers.

The challenge then was to present these strategies to parents in a simple and a user friendly approach. The traffic light system was developed as a good format to organise the strategies. Initially, there were two levels of strategies. These were proactive approach (Green light), this is implemented when the child is calm, and the reactive approach (Red light) to be used when the child is anxious. However, the researcher also considered the intermediate level, when the child is starting to be worried, or at a lower level of anxiety. On this basis, it was essential to develop another level of strategies (Amber) and called it the communication strategies. The traffic light system of strategies is illustrated in chapter 5, figure 5 (e).

It should be indicated that the “grading anxiety” strategy, which used numbers or pictures to express the level of the anxiety, was modified as the “anxiety scale-thermometer”. Whereas participants’ insight into the grading strategy approach used just pictures, or numbers for anxiety level, the researcher developed the “Anxiety scale- thermometer” to be an indicator for the child’s anxiety when it increased. This thermometer probably helps parents to identify the child’s anxiety level. This Anxiety scale- thermometer ranges from 0 (no anxiety: Green level on the traffic light system), to 1 (low anxiety: amber light on the traffic light system) and finally to 3 and 4 (High anxiety: the red level on the traffic light system). The idea of developing the thermometer was for two main reasons. Firstly, following identifying the anxiety, parents could deal with the child’s anxiety by choosing the appropriate strategy from the traffic light strategies. Secondly, this is a good way of developing communication between the child and parents regarding his anxiety. Talking with children about worries is often helpful (FPLD 1997). Furthermore, the child needs to learn how they can measure his or her fear in order to control it better. It has been suggested that it is helpful for the child using the anxiety scale in different situations through the day to be more aware of his / her anxiety level (Rapee et al. 2008). The literature validates the use of the anxiety scale thermometer for anxiety in children. This strategy has been suggested to be used by parents in managing anxiety

with typically developing children (Rapee et al. 2008).

Overall, the Calm Child Programme consisted of 10 strategies, which were organised based in three approaches. This programme considered appropriate management strategies for anxiety in children and young people with LD and autism. It proposed three types of management strategies including: proactive, communication and reactive strategies. Proactive strategies aimed at crisis prevention, and were recommended to be used on a daily life basis to prevent triggering anxiety. The second level was to communicate with the child when he begins to become anxious. And finally the reactive strategies were recommended when the child suffers from severe anxiety. As a consequence, the parents' information booklet "Calm Child Programme" was developed based on the consensus of expert panel and parents', carers, and teachers' experiences. These different strategies at different levels were intended to complement each other.

### ***The Calm Child Programme***

The Calm Child Programme was specifically designed and developed for parents who have a child / young people with a learning disability and autism. The ultimate aim of this programme was to support parents to help children and young people with autism and LD to manage their anxiety. This programme involved providing parents with 10 core child management strategies. Four of these strategies were designed to prevent trigger anxiety (i.e. talking and explaining with children, physical activities, visual schedule / time table and relaxation), and one strategy was to help the child to communicate and talk about his fears and worries (anxiety scale thermometer). In addition, the other five strategies focused on helping parents manage children's / young people's high anxiety (i.e. diversion, have a little fun, reassurance, cuddling and quiet time).

The present findings concur with previous research that parents used some of these management strategies in training programmes for children with LD,

for instance the Stepping Stones Triple P-Standard programme (Plant & Sanders 2007), which is specifically designed for parents who have a child with a disability. The Triple P-Standard programme involved teaching parents 25 strategies to facilitate children's behaviour. The following are examples of these strategies: talking, quiet time, discussion, distraction, planning ahead and engaging activities. This Stepping Stones Triple P-Standard (Plant and Sanders 2007) has demonstrated its efficiency as a useful intervention for parents of children with developmental disabilities.

The "Calm Child Programme" aims to support parents to manage children's and young people's anxiety, which enhances family protective factors and reduces risk factors associated with severe emotional problems in children and young people with LD and autism. The "Calm Child Programme" has similarities with other interventions to support parents:

- Research in child and family behaviour therapy which has developed many useful behaviour change strategies, particularly research that focuses on rearranging antecedents of problem behaviour through designing more positive engaging environments for children (e.g. Plant & Sanders 2007; Sanders et al. 2001; Sanders 1996).
- Social learning models of parent-child interactions that highlight the reciprocal and bidirectional nature of parent-child interactions (e.g. Patterson 1982), and empowering parents to help their children (Williams & Heslop 2005).
- Developmental research on parenting in everyday contexts. The programme targets managing children's anxiety in naturally occurring everyday contexts, drawing on work that traces the origins of social and intellectual competence to early parent-child relationships (e.g. Hart & Risley 1995; White 1990).
- Parental involvement in their children's intervention. As pointed out in the literature, parents are a vital element in treatment outcomes and generalization to everyday life (Ozonoff and Cathcart 1998; Reavon and Hepburn 2003).
- Research from the field of developmental psycho-education that involves

not only appropriate explanations to the parents on the nature of the

problem, but also provides an overview for treatment (Revean and Hepburn 2006). The parenting programme, the “Calm Child Programme”, represents awareness regarding the anxiety symptoms and the risk factors of developing anxiety specifically in children with LD and autism, in addition to the main target on the management strategies for anxiety.

- Prevention / proactive intervention for children’s mental health. This programme has particular emphasis on using a proactive approach to prevent triggers, or factors that may enhance anxiety, for example building up a timetable, talking and explaining in advance.
  
- Mental health problems and anxiety often cause more distress to caregivers than core autism and LD (Hastings et al. 2006; Lecavalier et al. 2006). Research shows that parents of children with autism are more likely to be stressed or depressed compared to other parents (Heiman 2002; Koegel 2000; Hastings et al. 2006; Heiman and Berger 2008; Diggle, McConachie and Randle 2008). Due to these issues the family is more likely to reach a crisis point (Weiss 2008). The parental programme, the “Calm Child Programme”, can also help reduce the distressing emotional reactions of parents including depression, anger, anxiety and high levels of stress, especially within the parenting role (Tehee et al. 2009; White and Hastings 2004). Providing parents with a practical and appropriate programme of parental strategies helps to strengthen the family’s capacities to meet the needs of the child (Wang 2006).

#### **7.4. STUDY 3: IMPLEMENTING CALM CHILD PROGRAMME**

**Aim (4):** To implement and evaluate a programme “calm child programme” of management strategies with a small group of parents of children and young people with LD and autism.

In this study, the aim was to evaluate the effectiveness of the “Calm Child Programme”, for parents with children and young people with LD and autism. This research had a mutual effect for children and young people with LD and autism as well as for parental support. The present findings illustrated a reduction in the child’s anxiety after the implementation of the Calm Child Programme by parents for three months. 85% of participating children and young people reported statistically significant improvement of anxiety. Successful outcomes had been reported with relation to achieving managing and coping with anxiety in children and young people with learning disability and autism spectrum disorders. Furthermore, parents reported better management for anxiety with their children and young people.

The pilot study implemented and evaluated the effectiveness of the Calm Child Programme on anxiety in children and young people with LD and autism. The findings indicated significant improvement in anxiety for children and young people. There were statistically significant differences in children’s and young people’s anxiety between pre- and post-test using the Wilcoxon-test. The results showed that children and young people had statistically significant lower anxiety scores after completing the programme ( $P < 0.05$ ). Furthermore, parents who implemented the programme were more likely to manage children’s and young people’s anxiety more positively. Parents’ ratings on the GAS-ID (Glasgow Anxiety Scale) revealed substantial decreases in children’s and young people’s overall anxiety symptoms from exhibiting high anxiety to no anxiety and for one case lower anxiety level. As well as evaluating the statistical significance of the impact of the Calm Child Programme, the qualitative significance of implementing the programme was also evaluated. This was an important process because this helps to provide complementary information and enhance the statistical analysis of the actual efficiency of the programme - the extent to which there is a recognizable difference in the child’s anxiety. Group discussions were conducted with parents to identify their feedback regarding implementing the programme. The group discussions emphasised the effectiveness of the consensus

strategies of managing the child's anxiety "Calm Child Programme". Parents reported benefits of implementing the strategies of managing their child's and young people's anxiety.

The results of this research indicate that most frequently used strategies were proactive approach. The focus of this facet of strategies was to prevent triggers for anxiety. These included building up a timetable, talking and explaining in advance, and regular physical activities. However, when the child started to become anxious, parents are recommended to communicate with the child, in an effort to support the child before his anxiety escalates. Early intervention by parents is more likely to be beneficial to prevent complications. Therefore, parents should be alerted to the signs of anxiety. These results are consistent with the literature which emphasises the importance of early support and intervention for emotional and behavioural problems in children with LD and autism to prevent further escalation of problems and unnecessary suffering (Herring et al. 2006; FPLD 2002).

Literature has indicated the importance of early intervention (Guralnick 1998). It is suggested that effective early intervention include approaches those prevent or arrest problems early in a child's life, or at early stages in the development of problem situations (Fish 2002). The Calm Child Programme is considered as early intervention approach. The potential issue of this programme is that these proactive strategies are helping parents to deal with the child's anxiety before it triggers. In addition, this programme is supporting parents on how to manage the anxiety with their children early in their life; before it reaches a crisis point. This can give parents and children confidence managing the anxiety and giving the best chance for success.

As part of the evaluation of the programme parents were asked on the group discussion to describe any changes in their child that they felt could be attributed to participation in the programme. Parents reported that the Calm Child Programme was helping to structure their life. They appreciated having

an explanation for their child's / young people's anxiety and symptoms and management strategies and felt better able to understand children's anxiety and manage it better. Many parents also reported that children and young people became calmer, more relaxed and more able to enjoy themselves. Additionally, participant evaluations for the programme showed that the majority of parents reported an improvement in their children's / young people's anxiety following the programme. It was interesting to note that many parents indicated that they would like to have had this booklet when their child was younger when he/she was just diagnosed with autism, as they had to find their own ways to deal with the child's anxiety. This suggests that parents had identified the use of the management strategies as an effective early intervention.

Another valuable outcome from implementing this programme was that of enhancing self-management in the children and young people. Self-management is a strategy in which a child keeps track of his/her own anxiety, for the purpose of decreasing and managing the anxiety. Although a self-management strategy was not included in the Calm Child Programme, the findings of this study suggested that children and young people used self-management strategies as a result of their parents implementing the programme. Several parents pointed out that children / young people started to use some strategies by themselves. This was a valuable strategy because it empowered the child to monitor and change his / her own anxiety. Participants in this research indicated that the use of the anxiety scale thermometer encouraged the child / young person to communicate with his parents the level / nature of his anxiety. This was either by pointing to his anxiety level on the scale, or by presenting the picture or the number card to let his parent know his level of anxiety. Parents reported that self management strategies were used in a number of ways; listening to calming music with himself, asking for a quiet time, and doing physical activities (e.g. exercise, going for a walk).

In addition, the Calm Child Programme provided parents with top tips to enhance generalization and maintenance of parenting strategies (i.e. be calm, plan ahead, understanding autistic features, go to child's own world...).

These allowed parents to apply parenting skills to a broad range of target behaviours at home and in community settings. Parents reported that the most specific tips to take away from this programme were: to be calm, to understand the autistic characteristics and child's / young people's anxiety, to distract the child before escalating his anxiety, to plan ahead, and to not force the child to do something he does not want. For instance, one of these tips was to plan ahead. When the parent knows what the child's fears are, the parent then needs to take one step further and establish what the child avoids (Rapee et al. 2008). The child with autism is often worried about change in routine, and avoids going into unknown situations by asking several questions so that situations won't be an unknown. Parents are most likely to answer the child's / young person's question and explain in advance of any unknown situation, and possibly try to plan ahead with a timetable. These findings agree with previous research which contain tips such as "plan ahead" and "be calm" as being associated with better anxiety management in children without disabilities (Rapee et al. 2008) and children with LD and behaviour problems (Quinn et al. 2007). This finding is consistent with the literature of anxiety in typically developing children and young people which emphasised the importance of parents being calm and not to respond angrily to their child's anxiety (The Mental Health Foundation 1997). In addition to understanding children's fears and worries, understanding the causes influencing this anxiety is important for parents (The Mental Health Foundation 1997).

Research suggests that children's anxiety can have a negative impact on their parents, as it has been discussed in the literature review chapter that parents caring for children with LD are more likely to suffer from depression and stress (Heiman 2002; Koegel 2000; Hastings et al. 2006; Heiman and Berger 2008; Diggle, McConachie and Randle 2008). Considerable evidence

has accumulated demonstrating that mothers of children with LD and autism are more likely to experience anxiety and stress, compared to other parents of children and young people without LD and autism (Hasting and Johnson 2001; Sivberg 2002; Weiss et al. 2002). Moreover, supporting parents appears to be helpful to relieve parental stress, along with managing a child's anxiety (Tehee et al. 2009; White and Hastings 2004; Creswell & Willetts 2007). Hence, the implementation of the Calm Child Programme by parents could bring another effect on reducing parental anxiety, although this research did not assess parental anxiety. The calm child programme appears to be helpful to reduce parents' anxiety. For instance, this could help to improve parents' coping skills and may enhance their ability to manage their own stress and anxiety. In particular, this programme provided parents with valuable tips for the anxiety management strategies.

It is interesting to illustrate that those parents of children and young people with LD and autism benefited from implementing the developed programme of parental management strategies. It is important to highlight that the traffic light system was helpful in the implementation of the Programme. Participants reported that this structured programme of three distinguished level of strategies was helpful to pick up the appropriate strategy easily. Furthermore, it was useful in structuring their daily life. Parents reported that organising the strategies into the three different levels of green, amber and red was user friendly for them. Organising the strategies in such order was easy for parents to choose which strategies could help to manage the anxiety at different levels in day to day life. For instance, the green group prevents the triggers of anxiety, and it always reminds parents how to plan the child's daily activities and to plan ahead his daily life. On implementing the strategies, children and young people tended to respond with any change in their daily routine when information was provided in advance. For example, mothers learned that they should talk and explain to their children / young people and also build up a visual schedule or timetable to provide information of ongoing events and any changes in the future events. The

amber strategies were recommended to parents to draw the parent's attention when their children / young people begin to be anxious. Parents were advised to utilize the red group of strategies when the child is agitated and very anxious.

Findings from this research suggest that parents were capable to support children and young people to manage their anxiety. This finding is consistent with Sofronoff & Attwood (2003) and Plant & Sanders (2007) illustrating the effectiveness of parents' involvement in interventions for children. For instance, Sofronoff et al. (2005) reported that parents' involvement enhanced the usefulness of CBT intervention programmes for anxiety in children with Asperger's syndrome. Furthermore, Plant & Sanders (2007) reported a significant reduction in child problem behaviour in implementing a behaviour parent training programme (Stepping Stones Triple P) for children with developmental disabilities.

The findings of the current study suggest that the Calm Child Programme is effective in managing the child's and young people's anxiety. The "Calm Child Programme" needs to be refined based on the feedback from participants. This programme should be then manipulated and evaluated with a larger sample of parents of children and young people with LD and autism. Furthermore, the long-term effectiveness of the programme needs to be evaluated by following up participants for a longer period of time.

#### **7.4.1. Recommended refinements of the programme**

According to parents' feedback, they suggesting that the "have a little fun" strategy would seem to be inadequate in the red group (high level of anxiety). Parents explained that if the child / young person has high anxiety, nothing is fun at this time. Hence, this strategy (have a little fun) would be relocated in the amber group, so that when parents identify any anxiety symptoms, they are encouraged to distract the child / young person to have

fun. The alteration made to this programme was to move the “have a little fun” strategy from the reactive facet of strategies to the communication facet which is the intermediate level of anxiety. The strategies will be as follows:

- I Proactive strategies (green): Talking and explaining, relaxation, physical activities, and visual schedule / timetabling.
- II. Intermediate level (amber): Anxiety scale thermometer and have a little fun.
- III. Reactive strategies (red): Distraction, quiet-out, reassurance and cuddling.

Another point was raised in terms of the use of the anxiety scale thermometer. Parents indicated that when children / young people communicate their anxiety level, it is unlikely to be true, as the children / young people in the current study were found to inform lower level of anxiety they were experiencing to their parents. Therefore, parents recommended that there should be a clear description in the parent’s information sheet regarding the use of this strategy: that its key use is as a kind of communication tool with the child, it empowers the child to monitor his anxiety. The child / young person also has the chance to communicate with his / her parent. The cam child programme is illustrated in Appendix –XII.

### ***Supporting parents***

Working with families has become widely accepted and is included as a recommended practice by professional associations (Sandall et al. 2004; Wang 2006). The ability of the parents of children and young people in the current research to implement the management strategies has indirect implications for broader theory of behavioural and parents training and intervention. Since the parental programme was found to be effective, it could be inferred that the participating parents were able to support their

children and young people in managing anxiety. This approach to the treatment and prevention of childhood disorders has the strongest empirical support of any intervention with children and young people (see Kazdin 1987; Sanders 1996; Taylor & Biglan 1998; Webster-Stratton & Hammond 1997).

There has been a tendency within the research community to view caring in pathological terms. There is abundant literature about family intervention and early intervention programmes for autism in children, for example the Son-Rise programme and ABA as discussed previously in the literature review chapter. There are positive aspects which emanate from the supporting parents programme, for instance parents' confidence, relieving parental stress, cost effectiveness, enhancing the capacities of the family, and quality of life. For instance, the Son-Rise programme is empowering parents in autism intervention. This provides parents with attitudinal training, listening to what they have to say, and providing them with the skills training they need to help their child like no-one else can. This programme helps parents to be confident directors and teachers for their own child's program (Son-Rise program, accessed 14<sup>th</sup> Sep. 2009).

A strong theme as a result of supporting parents is improving parents' confidence. Providing parents with a programme of the most appropriate and useful strategies to help their children and young people cope better with anxiety can increase the child's / young person's competency in coping with his anxiety as well as improving a parent's confidence (Plant and Sanders 2007), and the ability to manage the child's anxiety.

Interventions to support parents have a desire to promote positive aspects in relation to parental stress. Bringing up a child with LD and autism can be an overwhelming and traumatic experience for parents (Tehee et al. 2009). Many parents of children with LD and autism, and mental health problems, require coping strategies. Research has investigated the impact of

intervention for autism in children on families and especially factors associated with stress in parents, in order to ensure effective psychological support services (Grant et al. 1998). The Calm Child Programme can help specifically those parents who are stressed (Tehee et al. 2009; White and Hastings 2004) and help to relieve parental stress.

Supporting parents appears to be helpful to relieve parental stress and enhance family wellbeing (Tehee et al. 2009; White and Hastings 2004). Also, the intervention for supporting parents will help relieve parents' stress, along with managing a child's anxiety (Creswell & Willetts 2007).

The principle of involving parents in the intervention embraces not only empowering parents in children interventions, but also enhances the capacities of the family to meet the needs of the child (Wang et al. 2006; Blue-Banning et al. 2004; Turnbull et al. 2000). In addition, such a supporting parental programme can strengthen family ties, parents' resilience and coping strategies of family carers in everyday life (Grant et al. 1998; Grant & Whittell 2000). It is suggested that anxiety and frustration are associated with inconsistent and irregular support from services and lack of information was a major source of concern for the carers and families of people with LD (Chamber, Ryana, & Connor 2001). Therefore, presenting a supporting programme for parents to manage their children's problems and behaviour can have a positive impact on the caregivers and families.

Another potential aspect is by encouraging parents to interact in the intervention and to implement management strategies with the children, costs may be reduced for mental health services. Also it may help reduce the high workload of professionals (Smith et al. 2000; Mudford et al. 2001).

In brief, the "Calm Child Programme" is about supporting parents to support their children. This parental programme has selected positive strategies in

supporting parents with children and young people. The continued success of the “Calm Child Programme” depends on the development of the parents’ management and skills managing their children’s/ young people’s problems. More than this however, if we can develop a successful programme in supporting parents within this it will bring about improvement in parental skills and confidence and, thus, generated a good quality of life for all children, young people and parents. This programme is designed to help parents deal with one of the children’s and young people’s emotional problems to develop

a positive outlook for their children and young people's capabilities and potentials in addition to supporting parents. This supporting parent’s programme is designed to provide parents with appropriate and best practice management strategies programme. Moreover, this supporting parents’ programme can give parents hope and support through information about the child’s anxiety and providing such coping strategies for parents.

## **7.5. KEY ISSUES**

The findings of this research provide insight into the prevalence of anxiety in children and young people with LD and autism, present the development of a consensus of parental management strategies “Calm Child Programme” and discuss the implementation of this Calm Child Programme. There are several important findings of this research which contribute to the knowledge of anxiety in children and young people with LD and autism, and in supporting parents. In terms of anxiety in children, this research provides insight into the prevalence rates of anxiety in children and young people with mild to moderate LD and autism. Results from the screening study indicate that children and young people with mild to moderate LD and autism exhibited high prevalence rates of anxiety. The most important contribution of this research is developing the “Calm Child Programme” to support parents. The Calm Child Programme focused on the day-to-day experience of parents, carers and teachers to manage the children’s anxiety. Research findings

illustrate that the Calm Child Programme developed in this research demonstrated its usefulness in reducing the anxiety in children with LD and autism. Moreover, parents were capable of utilizing several effective coping strategies with their children to help their child manage and cope with their anxiety using the developed programme. These included talking and explaining in a simple way to the child, building a timetable, distraction, regular physical activities, and the relaxation approach. In addition, the Calm Child Programme facilitated self-management among those children with LD and autism in the pilot study.

This research differs from previous interventions for anxiety in several aspects. Previous research shows that the interventions were usually implemented by therapeutic professionals (e.g. Lindsay et al. 1989; Morrison and Lindsay 1997; Sofronoff & Attwood 2003; Reaven & Hepburn 2003). Furthermore, the most implemented intervention was cognitive behaviour therapy (CBT) which required professionals to apply its strategies. Some research involved parents of children as co-therapists in the intervention for their children (Sofronoff et al. 2005). This research presented life experiences from parents' and teachers' experiences and the opinion of expert panel of health professionals. Additionally, this research provided parents with practical and user friendly strategies which they can implement in their day-to-day life. Another key issue is that the "Calm Child Programme" has the potential to be a more cost effective method of intervention. When parents are involved in the intervention and implement management strategies with the children, this can help keep costs down of mental health services and also may help reduce the high workload of professionals (Smith et al. 2000; Mudford et al. 2001). Thus, the children's problems will be managed before they reach a crisis point and need more help and support from professionals and health services. In addition to supporting parents to deal with the child's anxiety, this programme presents a proactive approach of strategies preventing the child from developing a severe level of anxiety. This programme is consistent with the policy of "Every Child Matters" (DfES 2004), highlighting that the child should be supported to prevent reaching

crisis point.

The Calm Child Programme provides practical guidance for parents and caregivers on how to manage the children's anxiety by presenting 10 strategies that can be used in day-to-day life. The findings of this research indicated that parents have been able to support their children utilizing several effective strategies to manage and cope with anxiety. Furthermore, these management strategies were found to bring positive coping outcomes for children and young people with LD and autism. These findings agree with previous research that parents are an essential component for the

intervention (e.g. Diggle et al. 2008; Ozonoff and Cathcart 1998). This is an interesting point for further implications to encourage research to empower parents to be involved in the intervention for the mutual support of the child and parent.

Another strong theme from this research is helping parents have a better understanding of what their child is facing and seeing the world from their child's point of view. This could improve parent confidence and their ability to manage the challenges of their children's behaviour. Participants reported that it is important for parents and teachers to understand how the child with autism behaves and also about individual-specific autistic features in order to support and help their son / daughter to cope with his / her anxiety. This is a case in point: parents reported that identifying the causes of anxiety was useful to help prevent anxiety, for example noise may cause anxiety to the child with autism. Research shows that children with autism are often sensitive to noise (Grandin 1995; Trepagnier 1998; Aron & Aron 1997), and difficulties in sensory integration can lead to anxiety.

A further advantage of developing parental strategies is to help parents to have a better understanding of what their child / young person is facing and provide them with the most appropriate and useful strategies to help their children and young people cope better with anxiety and increase the child's

and young person's competency in coping with his anxiety, as well as improving a parent's confidence (Plant and Sanders 2007) and ability to manage the children's and young people's anxiety. Another potential advantage is by encouraging parents to interact in the intervention and to implement management strategies with the children and young people, this can keep costs of mental health services down and also it may help reduce the high workload of professionals (Smith et al. 2000; Mudford et al. 2001).

The key issues from this research are grouped under two main themes: 1) anxiety in children and young people and 2) involving and supporting parents in the intervention.

### **7.5.1. Anxiety in children and young people**

One of the main findings of this research is that children and young people with LD and autism have high prevalence rates of anxiety (32.6%). Findings from the parents' and teachers' interviews indicated that those children and young people experienced anxiety due to some antecedents, such as noise, darkness, dogs and cats, dentists, and changing routine. The current findings showed that anxiety in children and young people with LD and autism differs in important ways from children without disabilities. Parents reported that children exhibit anxiety due to any changes in routine, noise, or babies crying. These causes appeared to be due to autistic features. The most important finding regarding the anxiety in those children and young people was that the "Calm Child Programme" was effective in reducing and managing anxiety in those children.

The key benefits gained from this research were that children and young people were more able to cope with their anxiety and be more relaxed after receiving these management strategies. There was a significant statistical difference between pre and post-implementation of the Calm Child programme. The gains made by participants on this measure demonstrate the positive effect of the consensus of management strategies "Calm Child

Programme". The findings from this research demonstrated that the Calm Child Programme was effective in managing anxiety in children and young people with LD and autism. These findings suggest that further research should focus on parents in interventions. Considering that the current findings of this research indicated that parents of children and young people with LD and autism were capable to manage children"s and young people"s anxiety, it is reasonable to suggest that parents should be involved and empowered to support their children and young people in coping with their emotional and behavioural problems. There is therefore an ambitious road ahead for further research to focus on supporting parents. However, supporting parents, children and young people has the potential to improve well being of children and young people, and is a matter of great importance.

The development and implementation of the "Calm Child Programme" has shown that involving parents in interventions can play a vital role in involving parents to utilise a range of positive appropriate strategies for helping their children and young people manage anxiety. More interventions involving parents need to be developed to help prevent and overcome anxiety in children and young people with LD and autism. In this context, it should be prompt support for the children"s and young people"s anxiety through support which might be delivered by parents.

### **7.5.2. Policy and practice**

The Child and Adolescent Mental Health Services (CAMHs) highlight the importance of promoting the mental health and psychological wellbeing of young people with learning disabilities as well as their families (DOH 2004). It also emphasises the need for effective assessment, treatment and support for children and young people and their families. Anxiety management and clear intervention strategies for children and young people appear to be lacking. The lack of clear parental management strategies could have long term consequences. For parents of children and young people with LD and autism, the use of appropriate intervention is important to live an ordinary life

in the community. On this basis, it is essential to provide parents with management strategies that could help children and young people manage their anxiety.

Policies on children and families, like Every Child Matters (DfES 2004) and The National Service Framework for Children, Young People and the Maternity Service (NSF 2004), provide a context where the presumption is that there are specific standards to address the requirements of children and young people who are disabled and/or have complex health needs and their families (standard 8). This research has insight into the assessment and treatment of mental health for children with disabilities. This research screened for anxiety in children and young people with LD and autism, which

is the first step to address the children's, young people's and parents' need for interventions. Moreover, the development and implementation of the Calm Child Programme has contributed to supporting families of children with disabilities. The implementation of this programme revealed that supporting parents by providing the "Calm Child Programme" decreased children's anxiety.

### **7.5.3. Involving and supporting parents in interventions**

A unique feature of the present research is that this is the first study in the autism and learning disability children field that developed a programme of parental management strategies for anxiety in children with LD and autism. Results of the research emphasised the usefulness of the parenting programme, the "Calm Child Programme", in managing children's and young people's anxiety. The importance and benefit of parental involvement in the interventions of children have been well documented in previous research (e.g. Ozonoff and Cathcart 1998; Reavon and Hepburn 2003; Diggle et al. 2008; Sofronoff and Attwood 2003). Therefore parents' involvement in implementing management strategies is designed to help their children and young people with autism and LD to cope better in their life (Diggle et al.

2008).

#### **7.5.4. Policy and practice**

The recent programme of Aiming High for Disabled Children (Department of Children Schools and Families (DCSF) 2008) indicates commission work in related to the wider disabled children’s agenda to ensure added value to the programme. One of the delivery milestones of the core offer standards (2008) is to provide information to families and their children with disabilities. In the light of this agenda, the current research represents information on the positive strategies for parents to help their children and young people with LD and autism managing the anxiety.

The Aiming high for disabled children: core offer implementation materials (DH / DCSF 2008) provide standards for the delivery of services for disabled children and young people. The core offer sets out five standards for services for disabled children: information; transparency; assessment; participation; and feedback. These premises indicate that the core offer will empower parents by improving the information they receive and ensuring greater transparency of decision making. This transparency and information will help empower families with disabled children. Aiming higher for disabled children: better support for families launched in 2007 (DfES / HM 2007) was produced to address this issue and to help services to improve their support for children with a learning disability and their families “to provide effective support early in life and at key transition points, with early support for disabled children and their families, which promotes emotional and social development for disabled children and their families to help to improve outcomes for all enhancing equality and opportunity for them (DfES / HM 2007; PP. 9)

DfES guidance on inter-agency co-operation to improve the well-being of children states (2004; PP.13) “*Families are in most cases the key determinant of positive outcomes for their children, and good parenting is a*

*major factor in improving children and young people "s life chances".* Support to parents and carers has been identified as a priority nationally through National Service Framework for Children, Young People and Maternity Services; Every Child Matters, Change for Children programme and in line with this guidance the present research has been developed. The current policy relating to children "Every Child Matters" (DfES 2004 b) emphasises the importance of early intervention and ensuring necessary intervention takes place before the children reach crisis point. The present research supports this policy by encouraging parents to support children and implement some proactive strategies. In light of the UK policy "Every Child Matters" context for children and young people with LD (Department of Health 2004), this research was designed, giving the opportunity for those children, young people and families to have a good life.

Improving the Life Chances of Disabled People (2005) in England made an explicit commitment to "giving better support to families with young disabled children" (DOH 2005c). Therefore this research has sought to develop parenting management strategies that help children, young people and their parents cope better with mental health problems.

In recognising the role of supporting parents, the current research was conducted in the light of the UK children policy to support parents. One of the premises of Every Child Matters (DfES 2004) is increasing the focus on supporting families and carers, as they are considered the most critical influence on children "s lives. This was done by developing and implementing a Calm Child Programme, a consensus of useful management strategies for children"s and young people"s anxiety through parents. This research supports this interest in empowering parents to help their children and young people. Developing a Calm Child Programme is based on the premise that in providing parents with appropriate strategies for anxiety, they are better able to support their children and young people toward more positive coping and managing anxiety.

The context of the parents and their involvement is a basis for the children's wellbeing and good mental health. I was inspired by the participating parents' responses and came to see beyond the children's deficits. The parents' experiences with their children and how they contend with their anxiety management strategies has helped me to see how for these parents, as well as for their children, this is an ongoing process of learning, caring, understanding, accepting, and trusting. I aspire to understand better these children's difficulties and their parents' management strategies in order to facilitate successfully their children's wellbeing.

## 7.6. CONCLUSION

Mental health needs and interventions for children with LD and their families have increasingly drawn attention from researchers and policymakers. Parent's involvement in the intervention for their children and young people with LD and autism has increased and a wide range of parenting and home programmes are now widely available for parents. However, there has been very little research reported on the effectiveness of a programme of parental management strategies for anxiety in children and young people with LD and autism. The purpose of this research was therefore to develop a programme, in collaboration with parents, carers, teachers and health professionals, and then to ascertain the usefulness of this programme of management strategies for anxiety in children and young people with LD and autism. The findings of this research clearly suggested that children and young people with LD and autism demonstrated high prevalence rates of anxiety compared to previous research concerning children with LD but without autism. It is important to point out that the current research was the first in screening for anxiety in a population diagnosed with both LD and autism disorders. Assessing anxiety is the first step to intervention. Furthermore, the most interesting finding was the development of the "Calm Child Programme". This programme was based on parents', carers' and teachers' experiences in addition to the expertise of the health professionals of management strategies for anxiety in children and young people with LD and autism. The researcher is delighted to present this Calm Child Programme for parents of children with LD and autism disorders. This Calm Child Programme has practical and structured strategies for parents to manage children's anxiety. Most importantly, the findings of implementing the Calm Child Programme clearly suggest that the consensus of management strategies appeared to be effective in positively reducing the anxiety in children and young people as well as supporting parents in managing their child's anxiety. These results indicated that parents were capable of managing their children and young people's anxiety using the Calm Child Programme. These findings concur

with other research that also described involving parents as playing a vital role in supporting their children intervention (e.g. Chalfant et al. 2007; Plant and Sanders 2007; Sofronoff et al. 2005; Sheinkopf and Siegel 1998).

In brief, this research is important for supporting parents of children and young people with autism and learning disabilities as it provides the practical experience of management strategies from parents who experienced similar difficulties with their children and young people, and it presents also a professional's opinion about the appropriate management strategies for children with LD and autism. The findings presented in this research contributed to the knowledge of anxiety management and supporting parents of children and young people with LD and autism by developing a Calm Child Programme that significantly lowered the anxiety in children and young people with LD and autism.

## **CHAPTER 8: CONCLUSION & RECOMMENDATIONS**

### **8.1. INTRODUCTION**

This thesis set out to explore prevalence rates and management strategies for anxiety in children and young people with LD and autism. This chapter will recall the issues raised in this research and draw together the points and concepts discussed within this thesis. Based on the findings recommendations are outlined to support children and young people with LD and autism, and their parents. This chapter will also examine the limitations of this research and suggest areas for further research.

### **8.2. FOCUS OF THIS RESEARCH**

This research focuses on anxiety and parental management strategies for anxiety in children and young people with LD and autism. The primary aim of this research was to examine prevalence rates of anxiety and to develop and implement a Calm Child Programme, a consensus of management strategies for anxiety. This research utilised a mixed qualitative and quantitative methodology. The integration of various approaches of quantitative and qualitative methods was employed in order to address the aims of the research.

This research consisted of three interlinked studies. In study one; “screening study”, children and young people with LD and autism were screened for anxiety. The results showed that children and young people have high prevalence rates of anxiety (32.6%). In study two; “developing the Calm Child programme”, parents, carers and teachers were interviewed to explore the management strategies they used with their children and young people to manage anxiety. In stage two of this study, the information gathered from

parents, carers and teachers was discussed with an expert panel of health professionals to gain their opinion of anxiety management strategies and to develop a parental programme. A programme of management strategies called "Calm Child Programme" was developed to support parents. Finally, implementing the Calm Child Programme study, the Calm Child Programme was piloted with a small sample of parents caring for children and young people with LD and autism. A significant reduction in anxiety was reported in the children's / young people's anxiety after the use of the Calm Child Programme by parents. Parents reported benefits of implementing the strategies of managing their child's and young people's anxiety.

Over the past decade many interventions for mental health problems in children with autism have been documented in the literature. However they have not explored the theme of anxiety in children and young people with learning disabilities and autism. The main theme of this research was to explore anxiety in this population and to develop parental management strategies for supporting children and young people with LD and autism. This research represents a step towards gaining a better understanding of the parental management strategies for anxiety in children and young people with LD and autism. The results of piloting this programme indicate that parents successfully managed the children's and young people's anxiety; the children's and young people's anxiety reduced significantly after implementing the Calm Child Programme.

The contribution of this research lies in identifying the prevalence of anxiety in children and young people with mild to moderate LD and autism. Another important aspect of this research is the development of the "Calm Child Programme". The results of implementing this programme demonstrate how anxiety in children and young people with LD and autism can be better managed by supporting parents by providing a useful programme of anxiety management strategies for their children and young people. This finding has considerable importance for the families of children and young people with

LD and autism. Given the small size in implementing the Calm Child Programme, further study on a larger group is required in order to generalise its effectiveness.

### **8.3. IMPLICATIONS AND RECOMMENDATIONS**

This research has generated several ideas and recommendations related to anxiety in children and young people with LD and autism. These include:

Research findings indicated that children and young people with LD and autism have high prevalence rates of anxiety. Hence, a systematic assessment would be beneficial to identify this anxiety and to provide appropriate services to support their mental health. The Reiss Scale and Glasgow Anxiety Scale for children with Intellectual Disabilities (GAS-ID) were found useful for the assessment of anxiety, therefore these scales could be used in the assessment of anxiety in children and young people with LD and autism.

Findings of implementing the Calm Child Programme showed that management strategies and interventions targeting children and young people with LD and autism were successful through parental involvements in their children's interventions. In this context, parents' involvement in interventions is an approach that would merit its further use in clinical practice. Parents can provide excellent support for their children. Professionals can also learn a great deal from parents' experiences and perspectives in helping those children, young people and their families managing mental health problems. In order to develop effective programme of management strategies, it is important to explore the commonalities in the parents' experiences and health professionals' views. Yet, one should not forget that each family and person is unique, and each child has individual needs necessitating an individualised plan. The Calm Child Programme has

variety of strategies that parents can individualize them with their unique child. Some strategies might work with some individuals, but may not be either efficient or effective for others or might only be partially effective. Supporting and involving parents would be recommended in further research in children's interventions.

The developed programme "Calm Child Programme" suggested appropriate strategies for managing anxiety in children and young people with LD and autism. This programme is user friendly and easy to use. It offers a variety of strategies for parents to use in practical life. The pilot study of implementing this programme asserted the benefits of its use for both parents and children. For children and young people, they became calmer and a significant reduction of the anxiety was identified. Parents reported that the developed strategies were useful in managing their child's / young person's anxiety. Parents indicated that Calm Child Programme was helping to structure their life and children's and young people's life. Many parents also reported that children and young people became calmer, more relaxed and more able to enjoy themselves. Moreover, this programme facilitated self-management for the children and young people. For example, parents indicated that children started to manage their anxiety using some relaxation exercises, going for a walk, having a quiet time and listening to their favourite music.

This programme provided parents with effective and practical management strategies that helped to strengthen the family's functions and parents' confidence to manage the children's anxiety. Further research is needed to implement this programme with a larger number of parents of children and young people with LD and autism.

#### **8.4. LIMITATIONS**

This research may be deemed successful in relation to its exploratory aims.

Nevertheless, limitations were noted over the course of the research. These include challenges related to the nature of recruiting participants, data collection, and amount of data obtained. An implement limitation of the study is its small sample size. This research included data from 12 parents and 24 carers and teachers in developing a Calm child Programme. Not all the participants (parents and teacher) were interviewed for the same child. A number of factors contributed to the small sample size. Primarily, the number of eligible participants was limited to those who were known to the schools or social support groups. Participants' concern for privacy and confidentiality also contributed to the limitations of this study. Due to the confidentiality the researcher was not able to identify the parent and teacher of each child in developing the calm Child Programme study. Teachers were interviewed about the management strategies they used without giving the names of the children or young people. Due to the sample size, it was insufficient to examine differences among male and female participants.

Another limiting factor is about the instruments used for the screening study. For example, the Reiss Scale is standardised in the American population of children with LD. Therefore, the cut off score and its validity in an English population calls for further examination. Furthermore, this scale is designed for children with LD only not children with autism. The Glasgow anxiety scale used in this research was developed for children with LD not children with autism. Future research assessing anxiety in children with autism using GAS-ID is required.

One last potential limitation of the research findings was that they restricted the generalisation of the findings to the parents who live in Great Britain. This research was limited to children and young people with mild and moderate LD and autism. The use of this programme with children and young people with severe and profound learning disability needs further investigation. Second, because this is research based on the confines of the resources available in this PhD (e.g. time, funding), the implementation for the Calm Child Programme is a pilot study and replication with larger numbers is

desirable.

Overall, the findings offer several implications to be explored in future research. This research was successful in identifying appropriate management strategies for parents to manage children's and young people's anxiety.

## **8.5. IMPLICATIONS FOR FUTURE RESEARCH**

This research has provided key insights into the topic under investigation, and has generated ideas for future research. Developing Calm Child Programme a consensus of anxiety management strategies is a fairly recent addition to the research in the mental health care. This study has contributed to the growing literature needed to help in managing a child's anxiety. This has practical value in mental health care for children and young people with LD and autism. Implications derived from this research will be considered for future research on supporting parents for managing mental health problems in children and young people with LD and autism. A list of recommendations for future research is outlined below.

First, given the increased risk of developing anxiety for individuals with LD and autism, future research should address both assessment and treatment issues of this anxiety in a group that is already significantly challenged. As this is the first research to screen for anxiety in children and young people with mild – moderate LD and autism, replication studies with a larger sample size would be of great value.

Second, the screening instruments used in this research reported that children and young people with autism and LD are more vulnerable to anxiety. One of the important questions that arise from these findings is why children and young people with co-morbid LD and autism are associated with

high rates of anxiety. This identifies the need for further research examining the co morbidity of anxiety and autism. Also, screening is needed to identify

types and manifestation of anxiety that affect the lives of children and young people with LD and autism.

Third, future research could be conducted to identify the effectiveness of the anxiety management strategies implementing through corporations parents and teachers. It would be useful for teacher to work in partnership with parents. This kind of programme extends the duration and the depth of the programme from home to school, which could be used to better manage the children"s anxiety. Parents have a vital part to play in providing the love, understanding and consistency that their child needs. Many find that life at home goes more smoothly for everyone if they use consistent strategies or approaches that are also used by teachers or other professionals. However, a child"s behaviour can vary enormously in different environments.

Fourth, future research could be conducted to identify the factors that are enhancing successful intervention for children and young people with LD and autism should be addressed in further research.

Fifth, investigating the effect of individual characteristics (i.e. severity of autism, severity of LD, cognitive ability, language ability, and severity of anxiety symptoms, age, gender and temperament) on treatment outcomes is an important next step. Finally, further researches concerning all the aspects of parent- management programme for other mental health problems in that population are required.

Furthermore, future research could be conducted to identify the effectiveness of providing parents with specific workshops of implementing the "Calm Child Programme" of anxiety management strategies. Piloting of this programme was carried out with parents through postal correspondences. Parents were

contacted every fortnight by telephone during the three months implementing the programme. At the evaluation of the programme, participants indicated they would prefer there was a workshop before implementing the programme. They often receive many leaflets from services and would prefer having a practical session and live discussion. Organizing some workshops would be of value for parents. As it has been included in the programme information sheet, workshops could include a brief introduction in relation to the characteristics of children with LD & autism, how do children with autism show anxiety and the causes of anxiety in those children. Understanding this enabled them to manage their child's anxiety effectively and to prevent triggering the anxiety. Following this, strategies included in the Calm Child Programme should be explained. The focus of these workshops is to explore the programme and discuss the implementation of the different strategies of the programme. Parents would likely benefit from those workshops, explaining how parents can implement the Calm Child Programme with their unique child. Parents of children with autism and LD will have the chance to ask "how can I handle this with my child?". These workshops will help parents to share their experience with other parents in the same situation. It would be also interesting to study the impact of parent's workshop for the implementation of the "Calm Child Programme" on child's anxiety management.

Further research could be conducted to identify the impact of implementing this programme to parents after their child is diagnosed with autism. Parents identified that the Calm Child Programme would be highly effective and supportive if provided at the point of diagnosis of autism. For example, one participant mentioned in the group discussion of the programme after implementing the Calm Child Programme, she wish had these strategies when her child was young and just diagnosed with autism.

## **8.6. CONCLUSION**

The aim of this research was to identify prevalence of anxiety and to explore anxiety management strategies in children and young people with LD and autism. Up until now, there has been no published empirical research exclusively documenting management strategies for anxiety in the context of

children and young people with both LD and autism. The present research was undertaken to address this gap and develop and implement a consensus of parental management strategies “Calm Child Programme”. The Calm Child Programme was developed using Delphi method to identify consensus approach with professionals. The Calm Child Programme that emerged from parents’ experiences and health professionals’ views demonstrated that parents are capable of supporting their children and young people by managing their anxiety.

The key findings of this research indicate that:

- (a) The prevalence rates of anxiety in children and young people with LD and autism are high;
- (b) A wide range of management strategies were identified by parents, carers and teachers; and
- (c) The Calm Child Programme proved to be useful in reducing the children’s and young people’s anxiety significantly and supporting parents managing the children’s and young people’s anxiety.

The findings and implications of this research make contribution to the knowledge of the parental management strategies for anxiety in children and young people with LD and autism, while, at the same time, stimulating additional research into this promising and burgeoning field of inquiry. While findings may be limited to the population of mild to moderate children and young people with LD and autism, it is hoped that future research will be conducted to determine whether the management strategies being explored

is valid and reliable across LD and autism. Moreover, continued research is deemed vital in order to support parents, carers and teachers in finding effective managing and coping strategies. Several recommendations for continual research and treatment were discussed. This research has considerable importance for children and young people with LD and autism and families of such children and young people. The contribution of this research lies in identifying the prevalence of anxiety and the development of the “Calm Child Programme” of parental management strategies for anxiety in children and young people with LD and autism. Furthermore, a prevalence of anxiety in children and young people with LD and autism was also first identified. The findings clearly suggest how the anxiety in children and young people with LD and autism can be better managed by supporting parents and providing a useful programme of anxiety management strategies to their children and young people.

## **REFERENCES**

- Allen, D., & Davies, D. (2007). Challenging Behaviour and Psychiatric Disorders in Intellectual Disability. *Current Opinion in Psychiatry*, 20 (5), 450-455.
- Allington-Smith, P. (2006). Mental health of children with learning disabilities. *Adv Psychiatry Treat*, 12 (2), 130-138.
- Aman, M. G., Singh, N. N., Stewart, A. W., & Field, C. J. (1985). The aberrant behavior checklist: a behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency*, 89, 485 - 491.
- Amaral, D. G., Bauman, M. D., & Schumann, C. M. (2003). The amygdala and autism: implications from non-human primate studies. *Genes, Brain and Behaviour*, 2, 295-302.
- Amaral, D. G., & Corbett, B. A. (2003). "The amygdala, autism and anxiety. In *Novartis Foundation Symposium 251* (Ed.), *Autism: neural basis and treatment possibilities* (Vol. 251). Chichester: Wiley, PP. 177-1 97.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders (DSM-IV)*. Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders, Fourth edition - Text revision (DSM-IV-TR)*. Washington, DC: American Psychiatric Association.
- American Psychiatric Association (APA). (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth edition - DSM-IV*. Washington, DC: Author.
- Aron, E. N., & Aron, A. (1997). Sensory-processing sensitivity and its relation to introversion and emotionality. *Journal of Personality and Social Psychology*, 73, 345-368.
- Atladóttir, H. Ó., Parner, E. T., Schendel, D., Dalsgaard, S., Thomsen, P. H., & Thorsen, P. (2007). Time Trends in Reported Diagnoses of Childhood Neuropsychiatric Disorders: A Danish Cohort Study *Arch Pediatr Adolesc Med*, 161(2), 193-198.

- Arking, D. E., Cutler, D. J., Brune, C. W., Teslovich, T. M., West, K., Ikeda, M., et al. (2008). A Common Genetic Variant in the Neurexin Superfamily Member CNTNAP2 Increases Familial Risk of Autism. *American Journal of Human Genetics*, 82 (1), 160-164.
- Attwood, T. (1998). *Asperger's syndrome a guide for parents as professionals*. London: Jessica Kingsley Publisher.
- Bailey, N. M., & Andrews, T. M. (2003). Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation (DC-LD) and the diagnosis of anxiety disorders: a review. *Journal of Intellectual Disability Research* 47, 50 – 61.
- Baird, G., Cass, H., & Slonims, V. (2003). Clinical review: Diagnosis of autism *BMJ* 327, 488-493. [Online] DOI: 410.1 136/bmj.1327.7413.1488
- Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., et al. (2000). A Screening Instrument for Autism at 18 Months of Age: A 6-Year Follow-up Study. *Journal of American academy of child & adolescent psychiatry*, 39, 694-702.
- Baird, G., Pickles, A., Simonoff, E., Charman, T., Sullivan, P., & et al. (2008). Measles vaccination and antibody response in autism spectrum disorders. *Arch Dis Child*, 93 (10), 832-837.
- Baird, G., Simonoff, E., Pickles, A., & et al. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP) *Lancet* 368, 210–215.
- Barker, R. (Ed.). (2009). *Making sense of every child matters: Multi professional practice guidance*. Bristol: Policy press.
- Baron- Cohen, S. (1989). Do autistic children have obsessions and compulsions? *Br j Clin Psychol*, 28 (3), 193- 200.
- Baron- Cohen, S. (2004). Autism: Research into causes and intervention. *PEDIATRIC*, 7, 73-78.
- Baron- Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the Autistic Child Have a “Theory of Mind”? *Cognition*, 21, 385–395.
- Baron-Cohen, S. (1995). *Mindblindness An essay on autism and theory of mind*. London: The MIT press / Cambridge

- Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *British Journal of Psychiatry*, *161*, 839-843.
- Baron-Cohen, S., Cox, A., Baird, G., Swettenham, J., Nightingale, N., Morgan, K., et al. (1996). Psychological markers in the detection of autism in infancy in a large population. *British Journal of Psychiatry* *168* (2), 158-163.
- Baron-Cohen, S., Ring, H., Wheelwright, S., Bullmore, E., Brammer, M., Simmons, A., et al. (1999). Social intelligence in the normal and autistic brain: an fMRI study. *European Journal of Neuroscience*, *11* (1891-1898).
- Baron-Cohen, S., Ring, H. A., Bullmore, E. T., Wheelwright, S., Ashwin, C., & Williams, S. C. R. (2000). The amygdala theory of autism. *Neuroscience & Biobehavioral Reviews* *24* (3), 355-364.
- Baron-Cohen, S., Scott, F. J., & Allison, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry*, *194*, 500-509.
- Baron-Cohen, S., Tager-Flusberg, H., & Cohen, D. (1993). *Understanding other minds: perspectives from autism*. Oxford: Oxford University Press
- Baron-Cohen, S., Tager-Flusberg, H., & Cohen, D. (2000). *Understanding Other Minds. Perspectives from Autism and Developmental Cognitive Neuroscience* (2nd ed.). England, Oxford: Oxford University Press.
- Barrett, P. M. (1998). Evaluation of cognitive-behavioral group treatments for childhood anxiety disorders. *Journal of Clinical Child Psychology*, *27*, 459-468.
- Barrett, P. M., Dadds, M. R., & Rapee, R. M. (1996). Family treatment of childhood anxiety: A controlled trial. *Journal of Consulting and Clinical Psychology*, *64*, 333-342.
- Barrett, P. M., Rapee, R. M., Dadds, M. R., & Ryan, S. M. (1996). Family enhancement of cognitive style in anxious and aggressive children. *Journal of Abnormal Child Psychology*, *24*, 187-203.

- Bauman, M., & Kemper, T. (1988). Limbic and cerebellar abnormalities: consistent findings in infantile autism. *Journal of Neuropathology and Experimental Neurology*, 47, 369.
- Beail, N. (2003). What works for people with mental retardation? Critical commentary on cognitive-behavioural and psychodynamic psychotherapy research *Mental Retardation*, 41 (6), 468-472.
- Bejerot, S. (2007). An autistic dimension. *Autism*, 11 (2), 101-110. [Online] DOI: 110.1 177/1 362361 307075699.
- Bellini, S. (2004 a). Social skill deficits and anxiety in high functioning adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 19 (2), 78-86.
- Bellini, S. (2004 b). Living in fear: Anxiety in adolescents with autism spectrum disorders. *IRCA*, 9 (3), 1-2.
- Bellini, S. (2006). The Development of Social Anxiety in Adolescents With Autism Spectrum Disorders. *Focus on autism and other developmental disorders*, 21 (3), 138-145.
- Ben Itzhak, E., Lahat, E., Burgin, R., & Zachor, A. (2008). Cognitive behaviour and intervention outcome in young children with autism. *Research in Developmental Disabilities*, 29, 447-458.
- Berney, T. P. (2000). Autism - an evolving concept. *British Journal of Psychiatry*, 176, 20-25.
- Bertrand, J., Mars, A., Coleen Boyle, C., Frank Bove, F., Yeargin-Allsopp, M., & Decoufle, P. (2001). Prevalence of Autism in a United States Population: The Brick Township, New Jersey, Investigation *Pediatrics* 108 (5), 1155-1161.
- Bibby, P., Eikeseth, S., Martin, N. T., Mudford, O. C., & Reeves, D. (2002). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disabilities*, 23 (1), 81-104.
- Bloor, M. (2004). Addressing social problems through qualitative research In D. Silverman (Ed.), *Qualitative research: theory, Method and Practice*. London: Sage.

- Boon Hong, T.-C. (2002, a). Planning Physical Exercises for children with autism using structured teaching in the TEACCH approach *ARC*, 3 (2), 3-9.
- Boon Hong, T.-C. (2002, b). Teaching Individuals with High-functioning Autism Means of Coping with Anxiety. *ARC (S) Newsletter*, 3 (1).
- Borthwick-Duffy, S. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology*, 62, 17-27.
- Bouras, N. (1991). *Psychiatric and behavioural disorders in developmental disabilities and mental retardation*. Cambridge: Cambridge University Press.
- Bradley, E. A., Summers, J. A., Wood, H. L., & Bryson, S. E. (2004). Comparing rates of psychiatric and behaviour disorders in adolescents and young adults with severe intellectual disability with and without autism. *Journal of Autism & Developmental Disorders*, 34 (2), 151-161.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brereton, A., & Tonge, B. (2002). "Autism", In G. Holt & N. Bouras (Eds.), *Autism and related disorders*. UK: Henry Ling Limited, PP. 1-24.
- Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in Children and Adolescents with Autism Compared to Young People with Intellectual Disability. *Journal of autism and developmental disorders*, 36, 863-870.
- Brothers, L. (1990). The social brain: a project for integrating primate behaviour and neurophysiology in a new domain. *Concepts Neuroscience*, 1, 27-51.
- Brown, G. W. (2000). "Medical sociology and issues of aetiology", In M. G. Gleider, J. L. Lopez-Ibor & N. C. Andeason (Eds.), *Textbook of Psychiatry*. Oxford: Oxford University press.
- Brown, J., & Whiten, A. (2000). Imitation, Theory of Mind and Related Activities in Autism: An Observational Study of Spontaneous Behaviour in Everyday Contexts. *Autism*, 4 (2), 185-204.

- Brown, M., & Marshall, K. (2006). Cognitive behaviour therapy and people with learning disabilities: implications for developing nursing practice. *Journal of Psychiatric & Mental Health Nursing*, 13 (2), 234-241.
- Brown, R. T., Antonuccio, D. O., DuPaul, G. J., Fristad, M., King, C., Leslie, L., et al. (2002). *Childhood mental Health Disorders*. Washington, DC: American Psychological Association.
- Brownrigg, A. (2009). "Child and adolescent mental health services and Every Child Matters. In R. Barker (Ed.), *Making sense of Every Child Matters, multi professional practice guidance*. Bristol: The policy press, PP. 169-186.
- Buckley, S. (2002). Issues for families with children with Down syndrome, *Down Syndrome Issues and Information* [Online] DOI: 10.3104/9781903806265.
- Burnette, C., Mundy, P., Meyer, J., Sutton, S., Vaughan, A., & Charak, D. (2005). Weak central coherence and its relations to theory of mind and anxiety in autism. *Journal of autism and developmental disorders*, 35 (1), 63-73.
- California Department of Developmental Services. (2003). *Autism spectrum disorders. Changes in the California caseload. An update: 1999 through 2002*. Sacramento, CA: Department of Developmental Services.
- Cardaciotto, L., & Herbert, J. D. (2004). Cognitive behaviour therapy for social anxiety disorders in the context of Asperger's syndrome: A single case report. *Cognitive and behaviour practice*, 11, 75-81.
- Chadwick, O., Kusel, T., Cuddy, M., & Taylor, E. (2005). Psychiatric diagnosis and behaviour problems from childhood to early adolescence in young people with severe intellectual disabilities *Psychol Med* 35, 751-760.
- Chakrabarti, S., & Fombonne, E. (2001). Pervasive Developmental Disorders in Preschool Children. *JAMA*, 285 (27), 3093-3099.
- Chakrabarti, S., & Fombonne, E. (2005). Pervasive Developmental Disorders in Preschool Children: Confirmation of High Prevalence. *AM of Psychiatry*, 162 (1), 1133-1141.

- Chalfant, A. M., Rappee, R., & Carroll, L. (2007). Treating anxiety disorders in children with high functioning autism spectrum disorders: A controlled trial. *Journal of autism and developmental disorders*, 37, 1842-1857.
- Chappel, A. L. (2001). Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities*, 28 (1), 38-43.
- Charman, T. (2003). "Autism", In Novartis Foundation Symposium 251 (Ed.), *Autism: neural basis and treatment possibilities*. Chichester: Wiley.
- Chien-Yu Pan, & Frey, G. C. (2006). Physical Activity Patterns in Youth with Autism Spectrum Disorders. *Journal of autism and developmental disorders*, 36, 597-606.
- Child Development Institute. (2005). *All about childhood disorders: Learning Disabilities*. Available: <http://www.cdipage.com> (no date) (Accessed: 31<sup>st</sup> July 2006).
- Clark, D. B., Baker, B. L., & Heifetz, L. J. (1982). Behavioural training for parents of mentally retarded children: Prediction of outcome *American Journal of Mental Deficiency*, 87 (1), 14-19
- Clegg, J. (1999). Ethics and intellectual disabilities. *Current Opinion in Psychiatry*, 12 (5), 537-541.
- Clements, J. (1987). *Severe learning disability and psychological handicap*. Chichester: John Wiley and Sons.
- Cobham, V. E., Dadds, M. R., & Spence, S. H. (1998). The role of parental anxiety in the treatment of childhood anxiety. *Journal of Consulting and Clinical Psychology*, 66 (6), 893-905.
- Cooper, M., Hooper, C., & Thompson, M. (2005). *Child and adolescent mental health theory and practice*. London: Hodder Arnold.
- Cooper, S. A. (1997). Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *Br J Psychiatry*, 170 (4), 375-380.
- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors *British Journal of Psychiatry*, 190, 27 –35.

- Cooper, S.-A., Melville, C., & Morrison, J. (2004). People with intellectual disabilities. *BMJ*, 329 (7463), 414-415.
- Cooray, S. E., & Bakala, A. (2005). Anxiety disorders in people with learning disabilities. *Advances in psychiatric treatment*, 11, 355-361.
- Corbin, J., & Strauss, A. (2008). *Basic of qualitative research* (3rd Ed.). London: Sage.
- Costello, E. J., Angold, A., Burns, B. J., Stangl, D. K., Tweed, D. L., Erkanli, A., et al. (1996). The Great Smoky Mountains study of youth: goals, design, methods and the prevalence of DSM-III-R disorders. *Archives of General Psychiatry* 53, 1129-1136.
- Creswell, J. W. (2009). *Research design: qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks: Sage Publications.
- Croen, L. A., Grether, J. K., Hoogstrate, J., & Selvin, S. (2002). The changing prevalence of autism in California. *Journal of autism and developmental disorders*, 32 (3), 207-215.
- Croom, S. (2000). *Developing the capacity to respond to Child and Adolescent Mental Health (CAMH) needs: exploring how transferable nursing skills are to parents whose children have challenging behaviours*. Unpublished PhD thesis. University of Northumbria, Newcastle.
- Dagnan, D., & Jahoda, A. (2006). Cognitive - Behavioural Intervention for people with intellectual Disability and Anxiety Disorders. *Journal of Applied Research in Intellectual Disabilities*, 19 (2), 91-97.
- Dagnan, D., & Jahoda, A. (2008). The psychometric properties of the hospital anxiety and depressions scale adapted for use with people with intellectual disabilities. *Journal of intellectual disability research*, 52 (11), 942-949.
- Dales, L., Hammer, S., & Smith, N. (2001). Time trends in autism and in MMR immunization coverage in California. *J Am Med Assoc* 285, 1183 - 1185.
- Deb, S., & Prasad, K. B. (1994). The prevalence of autistic disorder among children with a learning disability. *The British Journal of Psychiatry*, 165, 395-399.

- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45 (6), 495-505.
- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 2: The rate of behaviour disorders among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45 (6), 506-514.
- DeBildt, A., Sytema, S., Kraijer, D., & Minderaa, R. (2005). Prevalence of pervasive developmental disorders in children and adolescents with mental retardation. *Journal of Child Psychology and Psychiatry*, 46 (3), 275-286.
- Dekker, M. C., & Koot, H. M. (2003). DSM-IV Disorders in Children With Borderline to Moderate Intellectual Disability. I: Prevalence and Impact. *J Am Acad Child Adolesc Psychiatry*, 42, 915-922
- Dekker, M. C., Koot, H. M., & Van der Ende, J. (2002). Emotional and behavioural problems in children and adolescents with and without intellectual disability *Journal of child Psychology & Psychiatry & Allied Disciplines*, 43 (1087-1098).
- Demicheli, V., Jefferson, T., Rivetti, A., & Price, D. (2005). Vaccines for measles, mumps and rubella in children. *Cochrane Database Syst Rev*, 4.
- Denscombe, M. (2003). *The good research guide for small-scale social research projects* (2nd ed.). England: Open University Press.
- DeMyer, M. K., Barton, S., Alpern, G. D., Kimberlin, C., Allen, J., & Steele, R. (1974). The measured intelligence of autistic children. *Journal of Autism and Childhood Schizophrenia* 4, 42-60.
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research* (2nd ed.). London: Thousand Oaks, Sage.
- Department of Health. (2004). *Disabled Children and Young People and those with Complex Health Needs: Change for Children - Every Child Matters. National Service Framework for Children, Young People and Maternity Services*. London: Crown.

- Department of Health. (2005 a). *An Overview of Cross Government Guidance, Every Child Matters Change for Children*. Nottingham: Crown.
- Department of Health. (2005 b). *Valuing people & making things better: The government's annual report on Learning disability* London: Department of Health.
- Department of Health. (2007). *Children's Health, our future: A review of progress against the National Service Framework for Children, Young People and Maternity Services 2004*. London: Department of Health.
- Department of Health (DOH). (1971). *Better Services for the Mentally Handicapped*. London: Crown.
- Department for Work and Pensions Family Resources Survey 2002-3 2004. (2004). *Statics for LD: Department for Work and Pensions Family Resources Survey 2002 -3 2004*, from [www.dwp.gov.uk/asd/frs/](http://www.dwp.gov.uk/asd/frs/)
- Department of Children Schools and Families. (2008). *Aiming high for disabled children: better support for families, Delivering the core offer standard*. London: Department of Health.
- Department of Health. (2008). *Valuing people now: from progress to transformation - a consultation on the next three years of learning disability policy*. London: Crown.
- Department of Health (DOH). (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century (cm. 5086)*. London: The Stationery Office.
- Deudney, C., & Shah. (2004). *Mental health in people with autism and Asperger's syndrome: a guide for health professionals*. London: National Autistic Society.
- DfCSF (Department for Children Schools and Families). (2009). *Special Education Needs a guide for parents and teachers*. London: Crown.
- DfES (Department for Education and school). (2001). *Special Education needs Codes of Practice*. London: Crown.
- DfES (Department for Education and skills). (2004). *Every Child Matters Children workforce strategy: A strategy to build a world-class workforce for children and young people*. London: Crown.

- DfES (Department for Education and skills). (2004). HM Government, Statutory Guidance on Interagency Co-operation to improve the well-being of Children: Children's Trusts.
- DfES (Department for Education and skills). (2004). *Disabled Children and Young People and those with Complex Health Needs: Change for Children - Every Child Matters. National Service Framework for Children, Young People and Maternity Services*. London: Crown.
- DfES (Department for Education and Skills) / HM Treasury. (2007). *Aiming High for Disabled Children: Better Support for Families*. UK: Crown.
- DiCicco-Bloom, B., & Carbtree, B. J. (2006). The qualitative research interview. *Making sense of qualitative interview*, 40, 314-321.
- Diggle, T., MaConachie, H., & Randle, V. R. L. (2008). Parents-mediated early intervention for young children with autism spectrum disorder (review). *Cochran Database of Systematic Review* (2).
- Dixon, M. S., & Gunary, R. M. (1986). Fear of dogs: group treatment of people with mental handicaps. *Ment Handicap*, 14, 6-9.
- Donovan, C. L., & Spence, S. H. (2000). Prevention of childhood anxiety disorders. *Clinical Psychology Review*, 20 (4), 509-531.
- Doody, G. A., Gotz, M., Johnstone, E. C., Frith, C., D, & Owens, D. G. (1998). Theory of mind and psychoses. *Psychological Medicine*, 28 (2), 397- 405.
- Dosen, A. (1993). "Mental health and mental illness in persons with retardation: what are we talking about?", In Flecher & A. Dosen (Eds.), *Mental health aspects of mental retardation*. New York: Lexington Books.
- Douglass, S., Plamer, K., & O'Connor, C. (2007). Experiences of running an anxiety management group for people with a learning disability using a cognitive behavioural intervention. *British Journal of Learning Disabilities*, 35 (4), 245-252.
- Eaves, L. C., Ho, H. H., & Eaves, D. M. (1994). Subtypes of autism by cluster

analysis. *Journal of Autism and Developmental Disorders*, 24, 3-22.

- Edelson, M. G. (2006). Are the Majority of Children With Autism Mentally Retarded?: A Systematic Evaluation of the Data. *Focus on autism and other developmental disabilities*, 21 (2), 66-83.
- Einfeld, S. L., & Tonge, B. J. (1995). The developmental behaviour checklist: the development and validation of an instrument to assess behavioural and emotional disturbance in children and adolescents with mental retardation. *Journal of autism and developmental disorders*, 25, 81-104.
- Einfeld, S. L., Tonge, B. J., & Rees, V. W. (2003). Longitudinal Course of Behavioral and Emotional Problems in Williams Syndrome *American Journal on Mental Retardation*, 106 (1), 73-81.
- Eisenhower, A., & Blacher, J. (2006). Mothers of young adults with intellectual disability: multiple roles, ethnicity and well-being. *Journal of Intellectual Disabilities Research*, 50 (12), 905-916.
- Emerson, E. (2001). *Learning disabilities: the fundamental facts*. London: The foundation for people with LD.
- Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47 (1), 51-58.
- Emerson, E., & Hatton, C. (2004). *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England*. Lancaster Institute for Health Research, Lancaster University, UK
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493 - 949.
- Emerson, E., & Hatton, C. (2008). *People with Learning Disabilities in England*. Lancaster University, UK: Centre for Disability Research.
- Emerson, E., Hatton, C., Bromely, J., & Caine, A. (1998). *Clinical psychology and people with intellectual disabilities*. UK: Wiley.
- Emerson, E., Hatton, C., Llewellyn, J., Blacker, J., & Graham, H. (2006). Soci-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of intellectual disability research*, 50 (12),

- Emerson, E., Robertson, J., & Wood, J. (2005). Emotional and behavioural needs of children and adolescents with intellectual disabilities in an Urban conurbation. *Journal of Intellectual Disabilities Research*, 49 (1), 16.
- Esbensen, A. J., Rojahn, J., Aman, M. G., & Ruedrich, S. (2003). Reliability and validity of an assessment instrument for anxiety, depression, and mood among individuals with mental retardation. *Journal of Autism and Developmental Disorders*, 33, 617–629.
- Evans, D. W. (2005). The Fears, Phobias and Anxieties of Children with Autism Spectrum Disorders and Down Syndrome: Comparisons with Developmentally and Chronologically Age Matched Children. *Child psychiatry and human development*, 36 (1), 3-26.
- Fact and Figures Department of Health. (2007). Learning disabilities: Fact and Figures: Department of Health, (Accessed: 2007). Available at: [www.learningdisabilities.org.uk/information/learning-disabilities-statistics/](http://www.learningdisabilities.org.uk/information/learning-disabilities-statistics/)
- Farrugia, S., & Hudson, J. (2006). Anxiety in adolescents with Asperger syndrome: Negative thoughts, behavioral problems, and life interference. *Focus on Autism and Other Developmental Disabilities*, 21, 25–35.
- Fish, E. (2002). The benefits of early intervention. *Stronger Families Learning Exchange Bulletin 2* (Spring/Summer), 8-11.
- Flynn, M., & Russell, P. (2005). Adolescents and younger adults. In G. Grant, P. Goward, M. Richardson & P. Ramcharan (Eds.), *Learning disability: A life Cycle Approach to Valuing people* Maidenhead Berkshire Open University Press.
- Fombonne, E. (2002). Epidemiological estimates and time trends in rates of autism. *Molecular Psychiatry*, 7 (Suppl 2), S4-6.
- Fombonne, E. (2003). Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Upe.... *Journal of Autism and Developmental Disorders*, 33 (4), 365-382.
- Fombonne, E. (2005). The changing epidemiology of autism. *Journal of Applied Research in Intellectual Disabilities* 18, 281-294.
- Fombonne, E. (2006). Epidemiology of autistic disorder and other pervasive

developmental disorders. *J Clin Psychiatry*, 66 (10), 3-8.

- Fombonne, E., & Chakrabarti, S. (2001). No evidence for a new variant of measles-mumps- rubellainduced autism. *Pediatrics*, 108, e56.
- Fombonne, E., Du Mazaubrun, C., Cans, C., & et al. (1997). Autism and associated medical disorders in a French epidemiological survey. *J Am Acad Child Adolesc Psychiatry* 36, 1561-1569.
- Fombonne, E., Simmons, H., Ford, T., Meltzer, H., & Goodman, R. (2001). Prevalence of pervasive developmental disorder in the British Nationwide Survey of Child Mental Health. *J Am Acad Child Adolesc Psychiatry*, 40, 820-827.
- Fombonne, E., Zakarian, R., Bennett, A., Meng, L., & McLean-Heywood, D. (2006). Pervasive Developmental Disorders in Montreal, Quebec, Canada: Prevalence and Links with Immunizations. *PEDIATRIC*, 118 (1), e139-150.
- Foundation for people with LD. (1997). *The anxious child: A booklet for parents and carers wanting to know more about anxiety in children and young people*. London: The Mental Health Foundation.
- Foundation for people with LD, Morgan, H., Jones, G., & Jordan, R. (2001). *Autistic Spectrum Disorders: A guide to services for adults with autistic spectrum disorders for commissioners and providers*. London: The mental Health Foundation.
- Foundation for People with Learning Disabilities (FPLD). (2002). *Count us in: The report of the committee of inquiry into meeting the mental health needs of young people with learning disabilities*. London: The Mental Health Foundation.
- Foundation for People with Learning Disabilities (FPLD). (2005). *Making us count: identifying and improving mental health support for young people with learning disabilities*. London: The mental Health Foundation.
- Freeman, B. J., & Van Dyke, M. (2006). Are the majority of children with autism mentally retarded? *Focus on autism and other developmental disabilities*, 21 (2), 86-88.

Frith, U. (1989). *Autism: explaining the enigma*. Oxford: Blackwell Scientific Publications.

- Frith, U., & Happe, F. (1994). Autism: beyond 'theory of mind'. *Cognition*, 50, 115-132.
- Gadow, K., Devincent, C. J., Pomeroy, J., & Azizian, A. (2004). Psychiatric symptoms in preschool children with PPD and clinic and comparison samples. *Journal of autism and developmental disorders*, 34 (4), 379-393.
- Gadow, K. D., & Speafkin, J. (1994). *Child symptoms inventory-4*. Stony Brook, NY: Checkmate Plus.
- Gadow, K. D., & Speafkin, J. (1997). *Adolescents symptoms inventory-4 screening manual*. Stony Brook, NY: Checkmate Plus.
- Gadow, K. D., & Speafkin, J. (1998). *Adolescents symptoms inventory-4 norms manual*. Stony Brook, NY: Checkmate Plus.
- Gadow, K. D., & Speafkin, J. (2002). *Adolescent symptoms inventory-4 screening and norms manual*. Stony Brook, NY: Checkmate Plus.
- Ghaziuddin, M. (2000). Autism in Mental Retardation. *Current Opinion in Psychiatry*, 13, 480-484.
- Ghaziuddin, M. (2002). Asperger syndrome: Associated psychiatric and medical conditions. *Focus on Autism and Other Developmental Disabilities*, 17, 138-144.
- Ghaziuddin, M., Alessi, N., & Greden, J. F. (1995). Life events and depression in children with pervasive developmental disorder. *Journal of autism and developmental disorders*, 25 (5), 495-502.
- Ghaziuddin, M., Weidmer-Mikhail, E., & Ghaziuddin, N. (1998). Comorbidity of Asperger syndrome: A preliminary report. *Journal of Intellectual Disability Research*, 42 (4), 279-283.
- Gillberg, C. (1986). Brief report: onset at age 14 of a typical autistic syndrome. A case report of a girl with herpes simplex encephalitis. *Journal of Autism and Developmental Disorders*, 16, 368-375.
- Gillberg, C. (1991). Outcome in autism and autisticlike conditions. *J Am Acad Child Adolesc Psychiatry* 30 375-382.
- Gillberg, C., & Billstedt, E. (2000). Autism and Asperger syndrome: coexistence with other clinical disorders. *Acta Psychiat Scand* 102, 321-330.

- Gillberg, C., & Coleman, M. (2000). *The biology of the autistic syndromes*. London: Mac Keith Press.
- Gillberg, C., & Wing, L. (1999). Autism: not an extremely rare disorder. *Acta Psychiatrica Scandinavica*, 99 (6), 399-406.
- Gillott, A., Furniss, F., & Walter, A. (2001). Anxiety in High-Functioning Children with Autism. *Autism*, 5 (3), 277-286.
- Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities*, 11, 359-370.
- Gillott, A., & Standen, P. J. (2004). Anxiety and stress in adults with autism. *Journal of Intellectual Disabilities Research*, 48, 321-339.
- Glesne, C. (1999). *Becoming qualitative researchers* (2nd ed.). New York: Addison Wesley Longman.
- Graham, P. (1991). *Child Psychiatry A developmental approach* (2nd ed.). Oxford: Oxford medical publication.
- Grandin, T. (1995). How people with autism think In E. Schopler & G. B. Mesibov (Eds.), *Learning and cognition in autism*. New York: Plenum Press, PP. 137-156.
- Grant, G. (2008). *Families invisible contributions and capital*. Paper presented at the 13th World Congress International Association for the Scientific Study of Intellectual Disabilities, Cape Town, South Africa.
- Grant, G., Flynn, M., & Ramcharan, P. (2008). *Resilience in families: re-thinking assessment, support and diversity*. Paper presented at the 13th World Congress International Association for the Scientific Study of Intellectual Disabilities, Cape Town, South Africa.
- Grant, G., Goward, P., Richardson, M., & Ramcharan, P. (2005). *Learning disability: a life cycle approach to valuing people*. Maidenhead: Open University Press.
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42 (1), 58-71.
- Grant, G., & Whittell, B. (2000). Differentiated Coping Strategies in Families with Children or Adults with Intellectual Disabilities: the Relevance of

- Gender, Family Composition and the Life Span. *Journal of Applied Research in Intellectual Disabilities*, 13 (4), 256-275.
- Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of intellectual disability research*, 50 (12), 970-976.
- Green, H., McGinnity, A., Meltzer, H., & et al. (2005). *Mental health of children and young people in Great Britain, 2004*. Basingstoke: Palgrave Macmillan on behalf of National Statistics.
- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27 (1), 70-84.
- Groden, J., Baron, M. G., & Groden, G. (2006). Assessment and coping strategies. In M. G. Baron, J. Groden, G. Groden & L. P. Lipsitt (Eds.), *Stress and coping in autism*. New York: Oxford University Press, PP. 15-41.
- Groden, J., Diller, A., Bausman, M., Velicer, W., Norman, G., & Cautela, J. (2001). The development of a stress survey schedule for persons with autism and other developmental disabilities. *Journal of Autism and Developmental Disorders*, 17, 207-217.
- Guralnick, M. J. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal of Mental Retardation*, 102 (4), 319-345.
- Hagopian, L. P., & Jennett, H. K. (2008). Behavioural Assessment and Treatment of Anxiety in Individuals with Intellectual Disabilities and Autism. *Journal of Dev and Phys Disabil*, 20, 467-483.
- Happe, F. (1994). *Autism: An introduction to psychological theory*. London: UCL press.
- Happe, F. (1996). Studying weak central coherence at low levels: Children with autism do not succumb to visual illusions. A research note. *Journal of Child Psychology and Psychiatry*, 37, 873-877.
- Happe, F. (1997). Central coherence and theory of mind in autism: Reading homographs in context. *British Journal of Developmental Psychology*, 15, 1-12.

- Hardy, D. J., O'Brien, A., Morrison-Nagatai, E., Skews, G., Ryan, T., & McNulty, N. (2004). Practical application of Delphi technique in bictural mental health nursing study in New Zealand. *Journal of Advancing Nursing, 64* (1), 95-109.
- Hare, D. J., Chapman, M., Fraser, J., Gore, S., & Burton, M. (2003). The prevalence of autistic spectrum disorders in people using a community learning disabilities. *Journal of Learning Disabilities, 7* (3), 267-281.
- Hartley, S. L., & McCoy, D. S. (2008). Prevalence and risk factors of maladaptive behaviour in young children with Autistic Disorder. *Journal of Intellectual Disability Research, 52* (10), 819-829.
- Hasson, F., & Et al. (2000). Issues involved in using Delphi technique. *Journal of Advancing Nursing, 32* (4), 1009-1015.
- Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behaviour problems of children with intellectual disabilities. *American Journal of Mental Retardation, 111*, 4861.
- Hastings, R. P., & Johnson, E. (2001). Stress in UK Families Conducting Intensive Home-Based Behavioural Intervention for Their Young Child with Autism. *Journal of autism and developmental disorders, 31* (3), 327-336.
- Hatton, C. (2002). Psychosocial interventions for adults with intellectual disabilities and mental health problems, a review. *Journal of Mental Health 11* (4), 357- 373.
- Heifetz, L. J. (1977). Behavioural training for parents of retarded children: Alternative formats based on instructional manuals. *American Journal of Mental Deficiency, 82*, 194-203.
- Heiman, T. (2002). Parents of Children with Disabilities: Resilience, Coping, and future expectations. *Journal of Developmental and Physical Disabilities, 14* (2), 156-171.
- Heiman, T., & Berger, O. (2008). Parents of children with Asperger's syndrome or with learning disabilities: Family environment and social support. *Research in Developmental Disabilities, 29* (4), 289-300.

- Henry, F., & Crabbe, M. D. (2002). "Treatment of anxiety disorders in persons with mental retardation", In A. Dosen & K. Day (Eds.), *Treating mental illness and behaviour disorders in children and adults with mental retardation*. USA: American psychiatric press, PP. 227.
- Herring, S., Gray, K. J., Tonge, T. B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, 50 (12), 874-882.
- Hill, J., & Furniss, F. (2006). Patterns of emotional and behavioural disturbance associated with autistic traits in young people with severe intellectual disabilities and challenging behaviours. *Research in developmental disabilities* 27 (5), 517–528.
- HM Government. (2004). Statutory Guidance on Interagency Co-operation to improve the well-being of Children. In Children's Trusts (Ed.).
- Holden, B., & Gitlesen, J. P. (2003). Prevalence of psychiatric symptoms in adults with mental retardation and challenging behaviour. *Research in developmental disabilities*, 24 (5), 323-332.
- Holt, G., & Bouras, N. (2002). *Autism and related disorders* UK: Henry Ling Limited.
- Holt, G., Gratsa, A., Bouras, N., Joyce, T., Spliller, M., & Hardy, S. (2004). *Guide to mental health for families and carers of people with intellectual disabilities*. London: Jessica Kingsley.
- Honda, H., Shimizu, Y., Misumi, K., Niimi, M., & Ohashi, Y. (1996). Cumulative incidence and prevalence of childhood autism in children in Japan. *The British Journal of Psychiatry*, 169, 228– 235.
- Hornig, M., Briese, T., Buie, T., & et al. (2008). Lack of Association between Measles Virus Vaccine and Autism with Enteropathy: A Case-Control Study. *PLoS ONE* 3 (9), e 3140.
- Howlin, P. (1998). *Children with autism and Asperger syndrome: a guide for practitioners and carers*. Chichester; New York: John Wiley.
- Howlin, P. (2000). Outcome in Adult Life for more Able Individuals with Autism or Asperger Syndrome. *Autism*, 4 (1), 63-83.

- Howlin, P., & Moore, A. (1997). Diagnosis in Autism: A Survey of over 1200 Patients in the UK. *Autism, 1*, 135-162.
- Hutcheson, H., Bradford, Y., Folstein, S., Gardiner, M., Santangelo, S., Sutcliffe, J., et al. (2003). Defining the autism minimum candidate gene region on chromosome 7. *Am J Med Genet 117B*, 90-96.
- Hutton, J., Goode, S., Murphy, M., Couteur, A., & Rutter, M. (2008). New-onset psychiatric disorders in individuals with autism. *Autism, 12* (4), 373-390.
- International Molecular Genetic study of autism consortium. (1998). A full genome screen for autism with evidence for linkage to a region on chromosome 7q. *Human Molecular Genetics, 7*, 571 - 578.
- Itzchak, E. B., Lahat, E., Burgin, R., & Zachor, A. D. (2008). Cognitive, behavior and intervention outcome in young children with autism. *Research in developmental disabilities, 28*, 447-458.
- Jackson. (1998). Focus group interviews as a methodology. *Nurse Research, 6* (1), 72-84.
- Jick, T. D. (1979). Mixing Qualitative and Quantitative Methods: Triangulation in Action. *Administrative science quarterly, 24* (4), 602-611.
- Jones, J., & Hunter, D. (1995). Qualitative research: Consensus methods for medical and health services research. *BMJ, 311* (5), 376-380.
- Joyce, T., & Hardys, P. (2003). Cognitive behaviour therapy and people with learning difficulties. *Living well, 3* (4).
- Juranek, J., Filipek, P. A., Berenji, G. R., Modahl, C., Osann, K., & Spence, M. A. (2006). Association between Amygdala volume and anxiety level: magnetic resonance imaging (MRI) study in autistic children. *Journal of Child Neurol, 21* (12), 1051-1058.
- Kanne, S. M. (2009). Psychiatric Symptoms and Psychosocial Disabilities in Young adults with autistic traits, *Journal of autism and developmental disorders* (Vol. January).
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217-250.
- Kanner, L., & Eisenberg, L. (1956). Early infantile autism 1943-1955. *Am J Orthopsychiatry 26*, 55-65.

- Kaptien, S., Jansen, D. E., Vogies, A., & Reijeneveld, S. A. (2007). Mental health problems in children with intellectual disability: use of the strengths and difficulties. *Journal of Developmental and Physical Disabilities, 52* (2), 125 - 131.
- Keeney, S., Hasson, F., & McKenna, H. P. (2001). A critical review of the Delphi technique as a research methodology for nursing. *International Journal of Nursing, 38*, 195-200.
- Kemper, T. L., & Bauman, M. L. (1993). The contribution of neuropathologic studies to the understanding of autism. *Neurol Clin, 11*, 175-187.
- Kenny, K., & McGilloway, S. (2007). Caring for children with learning disabilities: an exploratory study of parental strain and coping. *Journal of Compilation, 35*, 221- 228.
- Kern, L., Koegel, R. L., & Dunlap, G. (1984). The influence of vigorous versus mild exercise on autistic stereotyped behaviours. *Journal of Autism and Developmental Disorders, 14*, 57-67.
- Kielinen, M., Linna, S.L. & Moilanen, I. (2000) Autism in northern Finland. *European Child Adolesc Psychiatry, 9*, 162-167.
- Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L., & Wilson, F. J. (2000). The Prevalence of Anxiety and Mood Problems among Children with Autism and Asperger Syndrome. *Autism, 4* (2), 117-132.
- King, N. J., Josephs, A., Gullone, E., Madden, C., & Ollendick, T. H. (1994). Assessing the fears of children with disability using the revised fear survey schedule for children: a comparative study. *The British Journal of Medical Psychology, 67*, 377-386.
- Kirkland, J. (2005). Cognitive-behaviour formulation for three men with learning disabilities who experience psychosis: how do we make it make sense? . *British Journal of Learning Disabilities, 33* (4), 160-165.
- Kitzinger, J. (1995). Qualitative research: introducing focus groups. *British Medical Journal, 311*, 299-302.
- Kleinman, J., Marciano, P., & Ault, R. (2001). Advanced theory of mind in high-functioning adults with autism *Journal of Autism and Developmental Disorders, 31* (1), 29-36.

- Klin, A., Jones, w., Schultz, R., Volkmar, F., & Cohen, D. (2002). Defining and quantifying the social phenotype in autism. *American Journal of Psychiatry*, 159, 895-908.
- Knight, A., Clark, A., Petrie, P., & Statham, J. (2006). *The Views of Children and Young People with Learning Disabilities about the Support they Receive from Social Services: A Review of Consultations and Methods. Report of a review prepared for the DfES*. London: Thomas Coram Research Unit Institute of Education, University of London.
- Koegel, L. K. (2000). Interventions to Facilitate Communication in autism. *Journal of Autism and Developmental Disorders*, 30 (5), 383-391.
- Kraijer, D. (1997). *Autism and autistic-like conditions in mental retardation*. Lisse, The Netherlands: Swets & Zeitlinger.
- La Malfa, G., Lassi, S., Bertelli, M., Salvini, R., & Placidi, G. F. (2004). Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*, 48 (3), 262-267.
- La Malfa, G., & Notarelli, A. (1997). Psychopathology and mental retardation: An Italian epidemiological study using the PIMRA. *Research in developmental disabilities*, 18 (3), 179-184.
- Lainhart, J. E., & Folstein, S. E. (1994). Affective disorders in people with autism: a review of published cases. *Journal of autism and developmental disorders*, 24 (5), 587-601.
- Langlands, R. L., Jorm, A. F., Kelly, C. M., & Kitchener, B. A. (2008). First Aid Recommendations for Psychosis: Using the Delphi method to gain consensus between mental health consumers, carers, and clinicians. *Schizophrenia Bulletin*, 34, 435-443.
- Lecavalier, L. (2006). Behavioral and emotional problems in young people with pervasive developmental disorders: Relative prevalence, effects of subject characteristics, and empirical classification. *Journal of Autism and Developmental Disorders*, 36, 1101-1114.
- Lehmkuhl, H. D., Storch, E. A., Bodfish, J. W., & Geffken, G., R. (2008). Brief Report: Exposure and Response Prevention for Obsessive Compulsive

Disorder in a 12-year-old with Autism. *Journal of autism and developmental disorders*, 38 (977-981).

- Leong, J., Cobham, V. E., Groot, J. D., & McDermott, B. (2009). Comparing different modes of delivery: A pilot evaluation of a family-focused, cognitive-behavioral intervention for anxiety-disordered children. *Eur Child Adolescent Psychiatry*: [Online] DOI: 10.1007/s00787-008-0723-7.
- Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., et al. (2006). Comorbid Psychiatric Disorders in Children with Autism: Interview Development and Rates of Disorders. *Journal of autism and developmental disorders*, 36, 849-861.
- Li, H., & Morris, R. (2006). Assessing fears and related anxieties in children and adolescents with learning disabilities or mild mental retardation. *Research in Developmental Disabilities*, [Online] DOI: 10.1016/j.ridd.2006.06.001.
- Lidher, J., Martin, D., Jayaprakash, M., & Roy, A. (2005). Personality disorders in people with learning disabilities: follow-up of a community survey. *Journal of Intellectual Disabilities Research*, 49, 845-851.
- Lindsay, M. (1997). Emotional, behavioural and psychiatric disorders in children. In O. Russell (Ed.), *Seminars in psychiatry of learning disabilities*. London: Gaskell press.
- Lindsay, W., R. (1999). Cognitive therapy. *The psychologist*, 12, 238- 241.
- Lindsay, W. R., & Baty, F. J. (1986). Behavioural relaxation training: Explorations with adults who are mentally handicapped. *Mental Handicap*, 14, 160-162.
- Lindsay, W. R., Baty, F. J., & Michien, A. M. (1989). A Comparison of Anxiety Treatments with Adults Who Have Moderate and Severe Mental Retardation. *Research in Developmental disabilities* 10, 129-140.
- Lindsay, W. R., & Hastings, R. P. (2004). Cognitive assessment, cognitive models and cognitive therapy for people with intellectual disabilities: lessons from a special population. *Clinical Psychology & Psychotherapy*, 11 (4), 219-221.

- Lindsay, W. R., Howells, L., & Pitcaithl, D. (1993). Cognitive therapy for depression with individuals with intellectual disabilities. *British Journal of Medical Psychology*, 66, 135-141.
- Lindsay, W. R., Michie, A. M., Baty, F. J., & MacKenzie, K. (1988). Dog phobia in people with mental handicaps: anxiety management training and exposure treatments. *Mental Handicap Research*, 1, 39-48.
- Liss, M., Mailloux, J., & Erchull, M. J. (2008). The relationships between sensory processing sensitivity, alexithymia, autism, depression, and anxiety. *Personality and Individual Differences*, 45, 255-259.
- Lotter, V. (1966). Epidemiology of autistic conditions in young children: 1. Prevalence *Social Psychiatry*, 1, 124-173.
- Loughlin, K. G., & Moore, L. F. (1971). Using Delphi to achieve Congruent objectives and activities in a paediatrics department. *Journal of Medical Education*, 54 (2), 101 -1 06 as cited in Williams & Weeb 1994.
- Loveland, K. A., & Tunali-kotoski, B. (1997). The school-age child with autism In D. Cohen & F. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd Ed.). New York: Wiley, PP. 283 - 308.
- Mackenzie, F. (2005). The root of biomedical diagnosis. In G. Grant, P. Goward, M. Richardson & P. Ramcharan (Eds.), *Learning disability: a life cycle approach to valuing people*. Maidenhead: Open University Press.
- MacNeil, B., M, Lopes, V. A., & Minnes, P. M. (2009). Anxiety in children and adolescents with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 3, 1-21.
- Mahoney, G., Robinson, C., & Perales, F. (2004). Early motor intervention: The need for new treatment paradigms. *Infants and Young Children*, 17, 291-300.
- Masi, G., Brovedani, p., Mucci, M., & Favilla, L. (2002). Assessment of anxiety and depression in adolescents with mental retardation. *Child Psychiatry and Human development*, 32 (3), 227-237.
- Matson, J. L. (1991). A scale for evaluating emotional disorders in severely and profoundly mentally retarded persons. Development of the

- diagnostic assessment for the severely handicapped (DASH) scale. *British Journal of Psychiatry*, 159, 404-409.
- Matson, J. L., & Bamburg, J. W. (1998). Reliability of the assessment of dual diagnosis (ADD) *Research in Developmental Disabilities*, 19, 89-95.
- Matson, J. L., Kazdin, A. E., & Senatore, V. (1984). Psychometric properties of the psychopathology instrument for mentally retarded adults. *Applied Research in Mental Retardation*, 5, 81-89.
- Matson, J. L., Mahan, S., & LoVullo, S. V. (2009). Parent training: A review of methods for children with developmental disabilities. *Research in Developmental Disabilities*, 30 (5), 961-968.
- Matson, J. L., Smiroldo, B., Hamilton, M., & Baglio, C. S. (1997). Do anxiety disorders exist in persons with severe and profound mental retardation? . *Research in Developmental Disabilities* 18, 39-44.
- McCarthy, D. M., & Coleman, M. (1979). Response of intestinal mucosa to gluten challenge in autistic subjects. *Lancet*, 2, 877-878 (As cited in MRC 2001).
- McConachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *J Eval Clin Pract*, 13 (1), 120-129.
- McDougle, C., Kresch, L., Goodman, W. K., & Naylor, S. T. (1995). A case controlled study of repetitive thoughts and behavior in adults with autistic disorder and obsessive compulsive disorder. *American Journal of Psychiatry* 152, 772-777.
- McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioural treatment. *American journal on Mental retardation*, 97, 350-372.
- Medical Research Council (MRC). (2001). *Review of autism Research: Epidemiology and Causes*. London: Medical Research Council
- Melfsen, S., Walitza, S., & Warnke, A. (2006). The extent of social anxiety in combination with mental disorders. *European Child and Adolescent Psychiatry*, 15, 111-117.
- Meltzer, H., Gatward, R., Goodman, R., & Ford, T. (2000). *The report of a survey carried out in 1999 by Social Survey Division of the Office for*

*National Statistics on behalf of the Department of Health, the Scottish Health Executive and the National Assembly for Wales.* London: The Stationery Office.

MENCAP. (2008). *Learning Disabilities: Factsheet*. Available at: <http://www.mencap.org.uk/document.asp?id=1764&audGroup=&subjectLevel2=&subjectId=&sorter= 1 &origin=pageType&pageType= 1 08&pageno=4&searchPhrase=> (Accessed: 20 Feb 2009).

Mental Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. (2001). *Mental Health and Intellectual Disabilities Addressing the mental health need of people with Intellectual Disabilities*

Michaud, P., & Fombonne, E. (2005). Common mental health problems. *BMJ*, 330 (7495), 835-838.

Mindham, J., & Espie, C. A. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research*, 47 (1), 22-30.

Morgan, C., Roy, M., & Chance, P. (2003). Psychiatric comorbidity and medication use in autism: a community survey. *Psychiatr Bull*, 27 (10), 378-381.

Morgan, D. (1997). *Focus Groups as Qualitative Research* (2nd Ed.). Thousand Oaks, CA: Sage Publications Inc.

Morgan, V. A., Leonard, H., Bourke, J., & Jablensky, A. (2008). Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. 193, 364-372.

Moris, J., & Copestake, J. (1993). *Qualitative enquiry for rural development: A review*. Intermediate technology publication on behalf of the overseas developmental institute.

Morrison, A., & Barratt, S. (2010). What are the components of CBT for psychosis? A Delphi study. *Schizophrenia Bulletin*, 36 (1), 136-142, advance access online Oct, 2009.

- Morrison, F., & Lindsay, W. R. (1988). The effects of behaviour relaxation on cognitive performance in adults with severe mental handicap. *Unpublished manuscript, in Lindsay et al. 1998.*
- Morrison, F. J., & Lindsay, W. R. (1997). Reductions in self-assessed anxiety and concurrent improvements in cognitive performance in adults who have moderate intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 10* (33-40).
- Moss, S., Prosser, H., Costello, H., Simpson, N., Patel, P., Rowe, S., et al. (1998). Reliability and validity of the PAS-ADD Checklist for detecting psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research, 42*, 173–183.
- Mudford, O. C., Martin, N. T., Eikeseth, S., & Bibby, P. (2001). Parent-managed behavioral treatment for preschool children with autism: some characteristics of UK programs. *Research in Developmental Disabilities, 22* (3), 173-182.
- Muris, P., Hovee, I., Meesters, C., & Mayer, B. (2004). Children's perception and interpretation of anxiety-related physical symptoms. *Journal of behaviour therapy and experimental psychiatry, 35*, 233-244.
- Muris, P., Mayer, B., Vermeulen, L., & Hiemstra, H. (2007). Theory-of-mind, cognitive development, and children's interpretation of anxiety-related physical symptoms. *Behaviour research and therapy, 45*, 2121- 2132.
- Muris, P., & Steerneman, P. (1998). Comorbid Anxiety Symptoms in Children with Pervasive Developmental Disorders. *Journal of Anxiety disorders, 12* (4), 387-393.
- National Autistic Society (NAS). (2007). *What is autism?* London: NAS.
- National Health Service and Community Care Act (1990) *Part III Community Care: England and Wales*. Available at <http://www.opsi.gov.uk/ACTS/acts1990/Ukpga19900019en1.htm>
- National Institute for Clinical Excellence (NICE). (2002). *Schizophrenia: Core Interventions in the Treatment and Management of Schizophrenia in Primary and Secondary Care*. London: NICE.

- National Institute for Clinical Excellence (NICE). (2007). *Management of panic disorder and generalised anxiety disorder in adults*. London: National Institute for Health and Clinical Excellence.
- National Research Council. (2001). *Educating Children with Autism*. Washington DC.: National Academy Press.
- National Service Framework (NSF). (2004). *National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs*. London, Crown.
- NCBDDD. (2008). *National Center on Birth Defects and Developmental Disabilities at the U.S Centres for Diseases Control and Prevention*, Available at: <http://www.cdc.gov/ncbddd/index.html> (Accessed: 30<sup>th</sup> July, 2008).
- Neece, C., & Baker, B. (2008). Predicting maternal parenting stress in middle childhood: the roles of child intellectual status, behaviour problems and social skills. *Journal of intellectual disability research*, 52 (12), 1114-1128.
- NIASA (National Initiative for Autism: Screening and Assessment). (2003). *National Autism Plan for Children (NAPC)*. London: National Autistic Society.
- Nordin, V., & Gillberg, C. (1996). Autism spectrum disorders in children with physical or mental disability or both. I: clinical and epidemiological aspects. *Developmental Medicine and child Neurology*, 38, 297-313.
- O'Brien, G., & Pearson, J. (2004). Autism and Learning Disability. *Autism*, 8 (2), 125-140.
- Owen, D. (2001). The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients. *Methodological issues in nursing research*, 36 (5), 652- 658.
- Ozonoff, S., & Cathcart, K. (1998). Effectiveness of a home program intervention for young children with autism. *Journal of Autism and Developmental Disorders*, 28, 25-32.
- Pakenham, K., Sofronoff, K., & Samios, C. (2004). Finding meaning in parenting a child with Asperger's syndrome: correlates of sense making and benefit finding. *Research in Developmental Disabilities*, 25, 245-264.

- Palys, T. (1997). *Research decisions: Quantitative and qualitative perspective* (2nd ed.). Toronto: Harcourt Brace and Co.
- Parahoo, K. (1997). *Nursing Research Principles, Process and Issues*. London: Macmillan.
- Pastor, P., & Reuben, C. (2008). *Diagnosed attention deficit hyperactivity disorder and learning disability: United States, 2004-2006* (Vol. 10). National Center for Health Statistics: Vital Health Stat
- Peeters, T., & Gillberg, C. (1999). *Autism: Medical and Educational Aspects* (2nd ed.). Bognor Regis, UK: Wiley.
- Philippe, A., Martinez, M., Guilloud-Bataille, M., Gillberg, C., Rastam, M., Sponheim, E., et al. (1999). Genome-wide scan for autism susceptibility genes. Paris Autism Research International Sibpair Study. *Hum Mol Genet* 8, 805-812.
- Plant, K. M., & Sanders, M. R. (2007). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities*, 28, 362-385.
- Polkinghorne, D. (2005). Language and meaning: data collection in qualitative research. *Journal of Counselling Psychology*, 52 (2), 137-145.
- Powell, C. (2002). The Delphi technique: myths and realities. *Methodological issues in nursing research*, 41 (4), 376-382.
- Prout, H. T. (1993). Assessing psychopathology in persons with mental retardation: A review of the Reiss Scales. *Journal of School of Psychology*, 31, 535-540.
- Pyles, D. A. M., Muniz, K., Cade, A., & Silva, R. (1997). A behavioural diagnostic paradigm for integrating behaviour-analytic and psychopharmacological interventions for people with a dual diagnosis. *Research in Developmental Disabilities*, 18, 185-214.
- Quinn, M., Carr, A., Carroll, L., & O'Sullivan, D. (2007). Parents Plus Programme 1: Evaluation of Its Effectiveness for Pre-School Children with Developmental Disabilities and Behavioural Problems. *Journal of Applied Research in Intellectual Disabilities*, 20 (4), 345-359.

- Raghavan, R. (1998). Anxiety disorder in People with learning Disabilities: a review of literature. *Journal of learning Disabilities for Nursing, Health and social Care*, 2 (1), 3-9.
- Raghavan, R. (2004). Learning Disability and Mental Health: Reflections and future trends. *Journal of Learning Disabilities*, 8, 5-1 1.
- Raghavan, R., & Patel, P. (2005). *Learning disabilities and mental Health: A nursing perspective*. Oxford: Blackwell Publishing.
- Raghavan, R., & Pawson, N. (2008). Transition and social networks of young people with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 2 (3), 25- 28.
- Ramcharan, P., & Grant, G. (2001). Views and Experiences of People with Intellectual Disabilities and Their Families. (1) The User Perspective. *Journal of Applied Research in Intellectual Disabilities*, 14 (4), 348-363.
- Ramirez, S., & Lukenbill, J. (2007). Development of the fear survey for adults with mental retardation. *Research in developmental disabilities*, 28 (3), 225-237.
- Randall, P., & Jonathan. (1998). *Supporting the families of children with autism* Chichester: Wiley.
- Randall, P., & Parker, J. (1999). *Supporting the Families of Children with Autism*. Chichester: Wiley.
- Rapee, R., Psych, A., Spence, S., Cobham, V., & Lyneham, H. (2008). *Helping your anxious child* (2nd ed.). Oakland, CA: New harbinger
- Read, S. (1997). *Psychiatry in learning disability*. London W. B. Saunders.
- Reaven, J., & Hepburn, S. (2003). Cognitive-Behavioural Treatment of Obsessive- Compulsive Disorder in a Child with Asperger"s Syndrome: A Case Report. *Autism*, 7, 145-1 64.
- Reaven, J., & Hepburn, S. (2006). The parent's role in the treatment of anxiety in children with high functioning autism spectrum disorders *Mental Health Aspects of Developmental Disabilities* 9 (3), 73-8 0
- Reid, N. G. (1988). "The Delphi technique, its contribution to the evaluation of professional practice", In R. Ellis (Ed.), *Professional competence and quality assurance in Caring Professionals*. Kent: Croom-Helm, Beckenham, PP. 230-262.

- Reiss, S. (1990). Prevalence of dual diagnosis in community-based day programs in the Chicago metropolitan area. *American Journal on Mental Retardation*, 94, 578-585.
- Reiss, S. (1993). Assessment of psychopathology in persons with mental retardation. Cited In: R. Raghavan and P. Patel (2005)
- Reiss, S., & Valenti-Hein, D. (1990). *Reiss Scales for children's dual diagnosis for maladaptive behaviour* (2nd ed.). Chicago: International Diagnostic Systems.
- Reiss, S., & Valenti-Hein, D. (1990). *Reiss Scales for children's dual diagnosis: Test Manual*. Chicago: IDS Publishing Corporation.
- Reiss, S., & Valenti-Hein, D. (1994). Development of a psychopathology rating scale for children with mental retardation. *Journal of Consulting and Clinical Psychology* 62, 2833.
- Reynolds, J., Critchton, N., Fisher, W., & Sacks, S. (2008). Determining the need for ethical review: a three-stage Delphi study. *Research Ethics* 34, 889-894.
- Rice, C. (2007). Prevalence of Autism Spectrum Disorders Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000. *Morb Mort Wkly Rep Centre for Disease Control*, 56 (SS01), 1-11.
- Robson, C. (2002). *Real world research: a resource for social scientists and practitioner-research* Blackwell Publishers. (2nd ed.). Oxford: Malden, Mass.
- Rodgers, J. (1999). Trying to get it right: undertaking research involving people with learning difficulties. *Disability and Society*, 14 (4), 421-433.
- Rogers, S. J., Hepburn, S., & Wehner, E. (2003). Parent Reports of Sensory Symptoms in Toddlers with Autism and Those with Other Developmental Disorders. *Journal of autism and developmental disorders*, 33 (6), 631.
- Romanczyk, R. G., & Gillis, J. M. (2006). "Autism and the physiology of stress and anxiety. In M. G. Baron, J. Groden, G. Groden & L. P. Lipsitt (Eds.), *Stress and coping in autism*. New York: Oxford University Press, PP. 183-204.
- Ronald, M. (2008). *Helping your anxious child: a step-by-step guide for parents* (2nd ed.). Oakland, Calif: New Harbinger Publications.

- Rowe, G., & Wright, G. (1999). The Delphi technique as forecasting tool: issues and analysis *International Journal of Forecasting*, 15, 353-375.
- Royal College of Psychiatrists. (2004). *Psychiatric Services for Children and Adolescents with Learning Disabilities*. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists. (2006). *Psychiatric services for adolescents and adults with Asperger's syndrome and other autistic spectrum disorders*. London: Royal College of Psychiatrists.
- Rumsey, J. M., Rapoport, J. L., & Sceery, W. R. (1985). Autistic children as adults: Psychiatric, social, and behavioural outcomes. *Journal of American Academy of Child Psychiatry*, 24, 465-473.
- Rutter, M. (1978). Diagnosis and definition of childhood autism. *Journal of Autism and Developmental Disorders*, 6, 139-161.
- Rutter, M. (2005). Aetiology of autism: findings and questions. *Journal of intellectual disability research*, 49 (4), 231-238.
- Rutter, M., & Schopler, E. (1987). Autism and pervasive developmental disorders: Concepts and diagnostic issues. *Journal of Autism and Developmental Disorders*, 17, 159-186.
- Scherl, L., & Smithson, M. (1987). A new dimension to content analysis: Exploring relationships among thematic categories. *Quality and Quantity* 21, 199-208.
- Schopler, E., & Reichler, R. J. (1971). Parents as co-therapists in the treatment of psychotic children. *Journal of Autism and Childhood Schizophrenia*, 1, 87-102.
- Schwandt, T. A. (2001). *Qualitative inquiry: a dictionary of terms* (2nd ed.). Thousand Oaks, CA: Sage.
- Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). Brief Report Prevalence of Autism Spectrum Conditions in Children Aged 5-11 Years in Cambridgeshire, UK. *Autism*, 6 (3), 231-237.
- Seidel, M., Martin, P., & Hardung, S. (2007). Pervasive developmental disorders, and comorbidity *6th European Congress of Mental Health in Intellectual Disability Intellectual disability*. Zagreb, Croatia Faculty of Education and Rehabilitation Science, University of Zagreb.

- Shaked, M., Gamiliel, I., & Yirmiya, N. (2006 ). Theory of mind abilities in young sibling of children with autism. *Autism, 10* (2), 173-187.
- Sheinkopf, S. J., & Siegel, B. (1998). Home based behavioural treatment of young children with autism. *Journal of autism and developmental disorders, 28*, 15-23.
- Shulman, C., Bukai, O., & Tidhar, S. (2001). "Communicative intent in autism, In E. Schopler & N. Yirmiya (Eds.), *The research basis for autism intervention*. New York: Kluwer Academic/Plenum Publishers, PP. 117-1 33.
- Siegel, B. (1997). "Coping with the diagnosis of autism. In D. Cohen & F. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed.). New York: Wiley, PP. 745-766.
- Sigman, M. (1998). The Emanuel Miller Memorial Lecture 1997: changes and community in development of children with autism. *Journal of Child Psychology & Psychiatry, 39*, 817 - 827.
- Silverman, D. (1993). *Interpreting Qualitative Data: Methods for analysing talk, text and interaction*. London: Sage.
- Sim, J. (1998). Collecting and analysing qualitative data: Issues raised by the focus group. *Journal of Advanced Nursing* (28), 345-352.
- Simmonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*, 921-929.
- Sin, J., Moone, N., & Newell, J. (2007). Developing services for the carers of young adults with early- onset psychosis- implementing evidence based practice on psycho-educational family intervention. *Journal of psychiatric and mental health Nursing, 15*, 282-290.
- Sivberg, B. (2002). Family system and coping behaviour. *Autism, 6* (4), 397-409.
- Skews, G., Meehan, G., Hoot, S., & Armitage, P. (2000). Development and validation of clinical indicators for mental health nursing practice.

*Australian and New Zealand Journal of Mental Health Nursing*, 9 (1), 11-18.

- Smalley, S., Asarnow, A., & Spence, A. (1998). Autism and genetics: A Decade of Research. *Archives of general psychiatry* 45, 953-961.
- Smiley, E. (2005). Epidemiology of mental health problems in adults with learning disability: an update. *Advances in psychiatric treatment* 11, 214 - 222.
- Smith, C., Atkinson, J., McClelland, D., & Veroff, J. (1992). *Motivation and personality: Handbook of Thematic Content Analysis*. New York: Cambridge University Press.
- Smith, T., Buch, G. A., & Gamby, T. E. (2000). Parent-directed, intensive early intervention for children with pervasive developmental disabilities. *Research in developmental disabilities*, 21, 297- 309.
- Smith, T., & Lovaas, O. I. (1998). Intensive and early behavioral intervention with autism: The UCLA young autism project. *Infants and Young Children*, 10, 67-78.
- Society For The Autistically Handicapped. (2006). *What is Autism Pt. 1*, Available at <http://www.autismuk.com/index3.htm> (Accessed: 20<sup>th</sup> Oct 2006).
- Sofronoff, K., & Attwood, T. (2003). A cognitive behaviour therapy intervention for anxiety in children with Asperger's Syndrome. *Good Autism Practice*, 4 (1), 2-8.
- Sofronoff, K., Attwood, T., & Hinton, S. (2005). A randomised controlled trial of a CBT intervention for anxiety in children with Asperger's syndrome. *Journal of Child Psychology and Psychiatry*, 46 (11), 1152-1160.
- Son-Rise program. (2009). What is the Son-Rise programme? [http://www.autismtreatmentcenter.org/contents/aboutsonrise/whatisthe\\_son-rise\\_program.php](http://www.autismtreatmentcenter.org/contents/aboutsonrise/whatisthe_son-rise_program.php) (no date) (Accessed: 14<sup>th</sup> Sep. 2009).
- Spence, S. H. (1997). *The Spence Children's Anxiety Scale*. In I. Sclare (Ed.), *Child psychology portfolio*. Windsor, Canada: N FE R-Nelson.
- Stalker, K. (1998). Some Ethical and Methodological Issues in Research with People with Learning Difficulties. *Disability & Society*, 1, 5-19.

- Streubert, H., & Carpenter, D. (1999). *Qualitative Research in Nursing* (2nd ed.). Philadelphia: Lippincott.
- Strock, M. (2004). Autism spectrum disorders (Pervasive Developmental Disorders). In B. Department of Health and Human Services (Ed.), *National Institute of Mental Health (NIH)*: NIH publication No. NIH-04-5511 National Institute of Mental Health, National Institutes of Health, U.S.
- Sturmey, P. (2004). Cognitive therapy with people with intellectual disabilities: a selective review and critique. *Clinical Psychology & Psychotherapy*, 11 (4), 222-232.
- Sukhodolsky, D. G., Scahill, L., Gadow, K., Arnold, L., & et al. (2008). Parent-Rated anxiety symptoms in children with pervasive developmental disorders: Frequency and association with core autism symptoms and cognitive functioning. *J Abnorm Child Psychol*, 36, 117-128.
- Sullivan, K., Hooper, S., & Hatton, D. (2007). Behavioural equivalents of anxiety in children with fragile X syndrome: parent and teacher report *Journal of Intellectual Disability Research* 51 (1), 54-65.
- Summer, J., & Witts, p. (2003). Psychosocial intervention for people with learning disabilities; case study. *British Journal of Learning Disabilities* 31 (1).
- Szymanski, L., & King, B. H. (1999). Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, 38 (12), 1606–1610.
- Tantam, D. (2000). Psychological Disorder in Adolescents and Adults with Asperger's Syndrome. *Autism*, 4 (1), 47-62.
- Tantam, D., & Perestwood, S. (1999). *A mind of one's own: a guide to the specific difficulties and needs of the more able person with autism or Asperger's syndrome* (3rd ed.). London: National Autistic society.
- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of applied research in developmental disabilities*, 22, 34-42.

- The Mental Health Foundation. (1997). *The Anxious Child: A booklet for parents and carers wanting to know more about anxiety in children and young people*. London: The Mental Health Foundation.
- Thirion-Marissiaux, A., & Nader-Grosbois, N. (2008). Theory of Mind emotion““, developmental characteristics and social understanding in children and adolescents with intellectual disabilities. *Research in developmental disabilities, 29*, 414-430.
- Thomas, D., & Woods. (2003). *Working with people with learning disabilities: theory and practice* London: Jessica Kingsley.
- Tsai, L. Y. (1996). Brief report: Comorbid psychiatric disorders of autistic disorder. *Journal of autism and developmental disorders, 26* (2), 159-163.
- Tsai, L. Y. (2006). "Diagnosis and treatment of anxiety disorders in individuals with autism spectrum disorder“, In M. G. Baron, J. Groden, G. Groden & L. P. Lipsitt (Eds.), *Stress and coping in autism*. New York: Oxford University Press, PP. 388–440.
- Van den Hout, M., Arntz, A., & Merckelbach, H. (2000). "Contributions of psychology to understanding of psychiatric disorders“, In M.G. Gleder, J.L. Lopez-Ibor Jr & N.C. Andeason (Eds.), *Textbook of Psychiatry*. Oxford: Oxford University Press.
- Van der Bruggen, C., Stams, g. J., & Bogels, S. M. (2008). Research review: the relation between child and parent anxiety and parental control: a meta-analytic review. *Child Psychology and Psychiatry*, [Online] DOI: 10.1111 1/j.1 469-7610.2008.01 898.x.
- Wakefield, A. J., Murch, S. H., Anthony, A., Linnell, J., Casson, D. M., & et al. (1998). Ileallymphoid- nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet 351*, 637–641.
- Waller, N., & Furniss, F. (2004). Relationship between anxiety and autistic behaviour in persons with severs Learning disabilities. *Journal of Intellectual Disabilities Research, 48* (4, 5), 320.
- Wang, M., Summer, J., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early

- intervention programmes in assessing family quality of life. *Journal of Intellectual Disability Research*, 50 (12), 977-988.
- Weisbrot, D. M., & et al. (2005). The presentation of anxiety in children with pervasive developmental disorders. *J Child Adolesc Psychopharmacol*, 15 (3), 477-496.
- Weiss, J. A. (2008). *Family caregivers of adults with dual diagnosis: Unmet need and emergency serv.* Paper presented at the 13th World Congress International Association for the Scientific Study of Intellectual Disabilities, Cape Town, South Africa.
- Weiss, M. J. (2002). Hardiness and Social Support as Predictors of Stress in Mothers of Typical Children, Children with Autism, and Children with Mental Retardation. *Autism*, 6 (1), 115-130.
- Whitaker, S., & Read, S. (2006). The Prevalence of Psychiatric Disorders among People with Intellectual Disabilities: An Analysis of the Literature. *Journal of Applied Research in Intellectual Disabilities*, 19 (4), 330-345.
- White, N., & Hastings, N. R. (2004). Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities. *Journal of applied research in intellectual disabilities*, 17, 181-190.
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review*, [Online] DOI:10.1016/j.cpr.2009.01.003 (Accessed: 30 Jan 2009).
- Whitely, P., Rogers, J., Savery, D., & Shattock, P. A. (1999). Gluten free diet as an intervention for autism and associated spectrum disorders. *Autism*, 3, 45-65.
- William, R., Lindsay, R., & Hastings, P. (2004). Cognitive assessment, cognitive models and cognitive therapy for people with intellectual disabilities: lessons from a special population *Clinical Psychology & Psychotherapy*, 11 (4), 219-221.
- Williams, M. E., Atkins, M., & Soles, T. (2009). Assessment of Autism in Community Settings: Discrepancies in Classification. *Journal of autism and developmental disorders*, 39 (4), 660-669.

- Williams, P. L., & Webb, C. (1994). The Delphi technique: methodological discussion. *Journal of Advancing Nursing*, 19, 180-186.
- Williams, V., & Heslop, P. (2005). Mental health support needs of people with a learning difficulty: a medical or a social model? *Disability & Society*, 20 (3), 231-245.
- Willner, P., Jones, J., Tams, R., & Green, G. (2002). A Randomised controlled trial of the efficacy of a cognitive- behavioural anger management group for client with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 224-235.
- Wilson, A. (2004). Young people with anxiety and depression: a Phenomenological study. *Journal of Intellectual Disability Research*, 48 (4), 291-320.
- Wilson, A., Jahoda, A., Stalker, K., & Cairney, A. (2005). "What"s happening? How young people with learning disabilities and their family carers understand anxiety and depression", In Foundation for people with LD (Ed.), *Making us count*. London: Mental Health Foundation, PP. 37-61.
- Wing, L. (1976). "Epidemiology and theories of aetiology", In L. Wing (Ed.), *Early childhood autism*. Oxford: Pergamon Press, PP. 65–92.
- Wing, L. (1993). The definition and prevalence of autism: a review. *European Child and Adolescent Psychiatry*, 2 (2), 61-74.
- Wing, L. (1996). *The Autistic Spectrum: A Guide for Parents and Professionals*. London: Constable.
- Wing, L., & Attwood, A. (1987). "Syndromes of autism and typical development", In D. J. Cohen & A. M. Donellan (Eds.), *Handbook of autism and pervasive developmental disorders*. New York: Wiley & Sons, PP. 3-19.
- Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9 (1), 11-29.
- Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: is the prevalence rising?. *The epidemiology of autistic spectrum disorders: is the prevalence rising?*, 8 (3), 151-161.

- World Health Organization (WHO). (2000). *International classification of diseases- tenth edition-ICD-10-CM*. Salt Lake City: UT: Medicode, Inc.
- World Health Organization (WHO). (1993). *ICD-10 classification of mental and behavioural disorders*. Geneva: Author.
- World Health Organization (WHO). (1992). *ICD-10 Classification of Mental and Behavioural Disorders. Clinical Description and Diagnostic Guidelines*. Geneva: Author.
- Yirmiya, N., & Shulman, C. (1996). Seriation, conservation, and theory of mind abilities in individuals with mental retardation, and normally developing children. *Child Development*, 67 (5), 2045-2059.
- Zung, W. (1971). A rating instrument for anxiety disorders. *Psychosomatics*, 12, 371-379.

## **LIST OF APPENDICES**

	<b>PAGE</b>
Appendix - I Ethical approval	<b>2</b>
Appendix - II Ethical approval from university of Northumbria	<b>5</b>
Appendix - III Title of electronic journal	<b>6</b>
Appendix - IV Diagnostic Criteria for autism DSM-IV and ICD-1 0	<b>8</b>
Appendix - V Invitation letter for parents	<b>12</b>
Appendix - VI Young people information sheet	<b>13</b>
Appendix - VII Consent Form	<b>16</b>
Appendix - VIII Interview schedule	<b>17</b>
Appendix - IX Professional information	<b>19</b>
Appendix - X Focus group Schedule	<b>24</b>
Appendix - XI Reiss scales cut off scores	<b>28</b>
Appendix - XII Calm Child Programme	<b>29</b>
Appendix - XIII The parent"s invitation letter 2	<b>39</b>
Appendix - XIV Parents information leaflet	<b>40</b>
Appendix - XVI GAS-ID scale	<b>43</b>
Appendix - XVII Visual time table	<b>46</b>
Appendix - XIX Parent"s monitoring diary	<b>47</b>
Appendix - XX Parent"s evaluation sheet	<b>48</b>

**Appendix . I**  
**ETHICAL**  
**APPROVAL**



Top Floor  
Extension Block  
St Lukes Hospital  
Little Horton Lane  
Bradford  
BD5 0NA

Chairman: Professor Alan C Roberts  
OBE TD DL MPhil PhD DSc LLD FLS CBiol FIBiol  
Administrator: Sue Bell

Tel: 01274 365508  
Fax: 01274 365509

Email: sue.bell@bradfordhospitals.nhs.uk  
Email: alan.roberts@bradfordhospitals.nhs.uk

17 July 2006

Mrs Ereny S A Gobrial  
Research student  
Bradford University  
Unity building  
25 Trinity Road  
Bradford  
BD5 0BB

Dear Mrs Gobrial

Full title of study: An exploration of intervention and management Strategies for anxiety in young people with learning disabilities and autism  
REC reference number: 06/Q1202/45

Thank you for your letter of 29 June 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

#### Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

#### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	1	02 May 2006
Investigator CV		02 May 2006
Protocol	1	
Covering Letter		
Compensation Arrangements		01 August 2005
Participant Information Sheet: Parent/Guardian	1	
Participant Information Sheet: Young People	2	29 June 2006

Participant Information Sheet: Parent/carers	1	29 June 2006
Participant Information Sheet: Headteacher	1	29 June 2006
Participant Consent Form: Parent/Guardian	1	
Response to Request for Further Information		29 June 2006
Letter to Headteacher	1	
Timetable of PhD Thesis	1	

#### Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q1202/45

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Professor A Roberts  
Chairman – Bradford Research Ethics Committee

#### Enclosures:

*Standard approval conditions*  
*Site approval form*

Copy to: Research and Development Department  
School of Health Studies  
University of Bradford  
Unity Building  
25 Trinity Road  
Bradford

## Appendix - II

### ETHICAL APPROVAL FROM UNIVERSITY OF NORTHUMBRIA



School of Health, Community and Education Studies  
Postgraduate and Research Support Office  
Room H007  
Coach Lane Campus East  
Newcastle upon Tyne NE7 7XA

Tel: 0191 215 6276  
Fax: 0191 215 6605  
loma.kennedy@unn.ac.uk

14 May 2008

Ereny Gobrial  
3 Heathfield Crescent  
Cowgate  
NEWCASTLE UPON TYNE  
NE5 3EX

Dear Ereny

**School of HCES Research Ethics Sub Committee**

**Title: An exploration of intervention and management strategies for anxiety in young people with autism and learning disabilities.**

Thank you for your resubmission to the School Research Ethics Sub committee. I am pleased to inform you that University approval has been granted on the basis of this proposal and that the University Policies on Ethics and Consent are followed.

**Please note that all researchers must notify this office of the following:**

- Commencement and completion of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

A handwritten signature in black ink, appearing to be "G. O'Brien".

Professor Greg O'Brien  
Chair  
School Research Ethics Sub Committee

School of Health, Community and Education Studies  
Dean: Professor Royston Stephens

Northumbria University is the trading name of the University of Northumbria at Newcastle

## Appendix - III

### TITLE OF ELECTRONIC AND HAND JOURNALS SEARCHED

Title of journals electronic and hand searched of relevant articles used

---

**Title of the journal**

---

Advanced in Mental Health and Learning Disabilities

American Journal of Mental Retardation

American Journal of Psychiatry

Applied Behaviour of Psychiatry

Autism

British Journal of Psychiatry

British Journal of Developmental Disabilities

British Journal of Clinic Psychology

British Journal of Medical Psychology

Disability and Society

Health and Social Care

Journal of the Abnormal Psychology

Journal of Advanced Nursing

Journal of the American Academy of Child and Adolescent Psychiatry

---

Title of Journals electronic and hand searched of relevant articles used  
(Continued)

---

**Title of the journal**

---

Journal of Applied Research in Developmental Disability

Journal of Autism and Developmental Disorders

Journal of Intellectual and Developmental Disability

Journal of Behaviour Therapy and Experimental Psychiatry

Journal of Child Psychology and Psychiatry

Journal of Intellectual Disability Research

Journal of Psychiatric and Mental Health Nursing

Journal of learning disabilities for Nursing, Health & Social Care

Mental Retardation

Research in Developmental Disabilities

---

## Appendix . IV

### DIAGNOSTIC CRITERIA FOR AUTISM (DSM-IV-TR & ICD-10)

#### u **DSM IV for Diagnostic Criteria for Autism Disorders (2000):**

A diagnosis of autistic disorder is made when the following criteria from A, B, and C are all met.

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

qualitative impairment in social interaction, as manifested by at least two of the following:

- a. marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- b. failure to develop peer relationships appropriate to developmental level
- c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- d. lack of social or emotional reciprocity

qualitative impairments in communication as manifested by at least one of the following:

- a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- c. stereotyped and repetitive use of language or idiosyncratic language

- d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
  - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - b. apparently inflexible adherence to specific, non-functional routines or rituals
  - c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - d. persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

**u ICD- 10 (International Classification of Diseases) for Diagnostic Criteria for Autism Disorder (WHO 1993)**

**F 84 Pervasive developmental disorders**

This group of disorders is characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations, although they may vary in degree. In most cases, development is abnormal from infancy and, with only a few exceptions, the conditions become manifest during the first 5 years of life. It is usual, but not invariable, for there to be

some degree of general cognitive impairment but the disorders are defined in terms of behaviour that is deviant in relation to mental age (whether the individual is retarded or not). There is some disagreement on the subdivision of this overall group of pervasive development disorders.

### **F84.0 Childhood autism**

A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs in boys three to four times more often than in girls.

#### ***Diagnostic criteria***

To diagnose the autism spectrum disorders at least 8 of the 16 specified items must be fulfilled.

#### **a. Qualitative impairments in reciprocal social interaction, as manifested by at least three of the following five:**

1. Failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction.
2. Failure to develop peer relationships.
3. Rarely seeking and using other people for comfort and affection at times of stress or distress and/or offering comfort and affection to others when they are showing distress or unhappiness.
4. Lack of shared enjoyment in terms of vicarious pleasure in other peoples' happiness and/or spontaneous seeking to share their own enjoyment through joint involvement with others.
5. Lack of socio-emotional reciprocity.

#### **b. Qualitative impairments in communication:**

1. Lack of social usage of whatever language skills are present.
2. Impairment in make-believe and social imitative play.

3. Poor synchrony and lack of reciprocity in conversational interchange.
4. Poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes.
5. Lack of emotional response to other peoples' verbal and non-verbal overtures.
6. Impaired use of variations in cadence or emphasis to reflect communicative modulation.
7. Lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

**c. Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least two of the following six:**

1. Encompassing preoccupation with stereotyped and restricted patterns of interest.
2. Specific attachments to unusual objects.
3. Apparently compulsive adherence to specific, non-functional routines or rituals.
4. Stereotyped and repetitive motor mannerisms.
5. Preoccupations with part-objects or non-functional elements of play material.
6. Distress over changes in small, non-functional details of the environment.

**d. Developmental abnormalities must have been present in the first three years for the diagnosis to be made.**

## Appendix . V

### INVITATION LETTER FOR PARENTS



MAKING KNOWLEDGE WORK

Dear Parent / Guardian:

**RE: An exploration of management strategies for anxiety in children and young people with learning disabilities and autism**

I am a research student at the University of Bradford. I am doing a project on the help, support and management of children / young people with autism, who have autism, learning disabilities and anxiety. The aim is to look at the kinds of help / support / management models used by parents and teachers. I would like to talk to you about the types of management strategies used at home. All information from this discussion will be confidential and will only be used for the purpose of the project. This project has been approved by Bradford local research ethics committee (REC reference no. 06/Q1 202/45). Before talking to you, I need to screen your son / daughter for the anxiety, be sure that no contact at all with your child either in the screening phase using the anxiety scales, or the interview. All should be done with you.

I would very much appreciate your involvement in this study and would therefore be grateful if you could complete the following consent slip to me. If you require any more information regarding to this project I can be contacted on 01274 236380; [email:e.s.gobrial@bradford.ac.uk](mailto:e.s.gobrial@bradford.ac.uk).

Thank you

**Ereny Gobrial**

25 Unity Building, Trinity Road  
School of Health Studies, Bradford, UK  
BD5 0BB

---

I would like to be involved on, and would like more information about my project, please contact me

I would NOT like to be involved in the project. Please do not contact me.

Name of Parent/ carer \_\_\_\_\_

Child name \_\_\_\_\_ Age \_\_\_\_\_

Telephone \_\_\_\_\_ Email \_\_\_\_\_

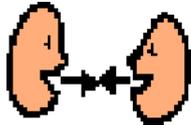
Signature \_\_\_\_\_ Date \_\_\_\_\_

Appendix . VI

YOUNG PEOPLE INFORMATION SHEET



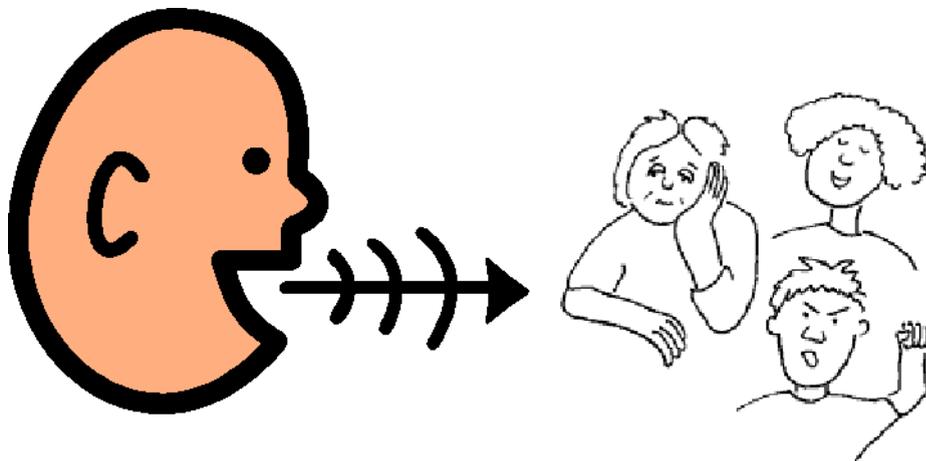
INFORMATIN SHEET FOR YOUNG PEOPLE



I am doing a project about the types of help and support for anxiety with young people with learning disabilities and autism.



We would like to run some sessions dealing with your worries



I would to talk to you about my project:

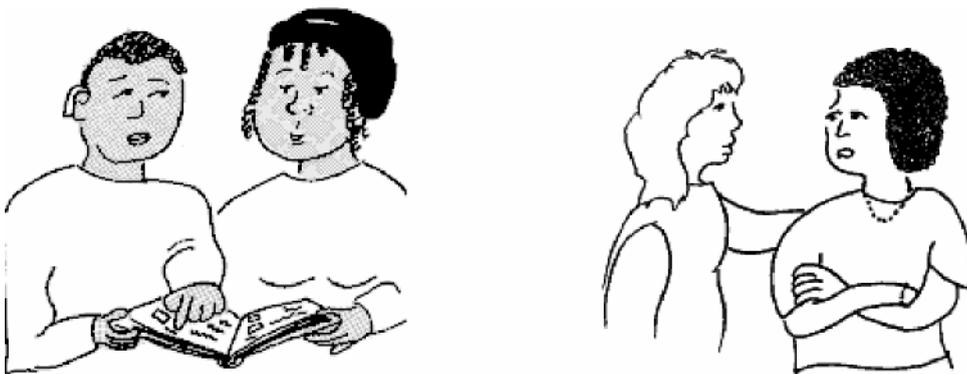
(1) I would to talk to you about any worries you have.

(2) I would like to talk to your Mum, teacher about your worries



The meetings with your Mum, teacher will be tape-recorded.

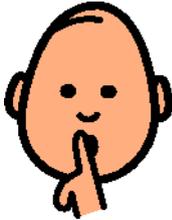
You may show this letter to your carers and talk to them about it.



You do not have to take part in this project and can say 'No' if you do not wish to take part.



You will be able to speak freely about any of your worries. All the information that you tell me will be confidential and will not be discussed with anyone else.



Please feel free to contact me (Ereny Gobrial) at 01274 236380 if you wish more information.

Thank you for your time.

Yours sincerely,

***Ereny Gobrial***

**Appendix - VII**

**CONSENT FORM**

Parent Identification Number for this trial:

**CONSENT FORM**

**Title of Project:**

**“An exploration of management strategies for anxiety in children and young people with learning disabilities and autism”**

Name of Researcher: ***Ereny Gobrial***

**Please initial box**

1. I confirm that I have read and understand the information sheet dated \_\_\_\_\_ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
  
3. I agree to take part in the above study.

\_\_\_\_\_  
Name of Parent / teacher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed, 1 for parents; 1 for researcher site file

## Appendix .VIII

### INTERVIEW SCHEDULE

#### **Semi structured Interview Schedule**

Hello, my name is Ereny, I am PhD student at University of Bradford; I am doing PhD thesis on management strategies for anxiety in children and young people with learning disabilities and autism.

Thank you for being willing to take part in the follow -up interview to the previous survey. Can I first of all assure that you will remain completely anonymous and no records of the interview will be kept with your name on them, your response will be treated in strictest confidence. Do you mind if I tape- record the interview, once I transcribe the interview, the tape will be destroyed. It won't be used for any other purpose.

Please, feel free if you find some of the questions far-fetched, silly or difficult to answer, feel perfectly free to interrupt.

1. I would like to start by asking a few questions about your son! daughter:
  - a. What are the types of worries ! fears?
  - b. Can you tell me what are symptoms when your child being anxious or worried?
  - c. Do you think these worries ! fears are a problem for him! her and you?  
(How)?
2. Are you able to identify the source of these stress ! anxiety on your son ! daughter? What are factors do you think behind these fears?
3. Is it difficult to keep your child relaxed ! calm when he!she suffering of anxiety symptoms?
4. Do you receive any professional help or support relation to your son ! daughter?  
If yes, is this help in relation to your son ! daughter fears?

5. I'm interested in your experiences of management anxiety of your son/ daughter, Can you give me an example of actions (steps) or things you have used to deal with your child anxiety"s / fears?
6. Have you tried any other **approaches** / methods that you found useful?  
And **how many times** do you use these strategies with your son/ daughter?

1.	Strategies	Day	week	Month
2.				
3.				
4.				

9. Can you list the changes you have seen in your son / daughter since using management strategies for anxiety disorder?

- 1)
- 2)
- 3)

10. Can you describe how he / she felt when you started these approaches?

11. Do you think these approaches are actually working?

12. Do you try many anxiety management techniques? Can you determine what helps most?

13. How old your child now?

- a) Did you use different techniques when s/he was small?
- b) Do you think those methods used when s/he was a child do not work now when s/he has grown up?

14. Can I finally ask you if you think there is any aspect of your experience of looking for treating / managing anxiety that has not been covered in this interview?

***Thank you very much for helping us and giving  
your time I appreciate your help.***

## Appendix . IX

### PROFESSIONAL INFORMATION SHEET



School of Health, Education,  
and community

Dear Professional:

**RE: An exploration of management strategies for anxiety in children and young people with learning disabilities and autism**

I am a research student at the University of Northumbria. I am doing a project on the help, support and management of children / young people with autism, who have autism, learning disabilities and anxiety. The aim is to look at the kinds of help/ support /management models used by parents and teachers. We had done interview survey with parents and teachers regarding the management strategies they used, and it was effectively reduced their children"s anxiety. This project has been approved by Bradford local research ethics committee (REC reference no. 06/Q1202/45) and Northumbria University. The current stage is developing consensus models about the management strategies for anxiety in children and young people with LD and autism.

I would very much appreciate your involvement in this study and would therefore be grateful if you could complete the following management evaluation sheets.

Thank you

***Ereny Gobrial***

## **An exploration of management strategies for anxiety in children and young people with learning disabilities and autism**

**Aim:** Develop a consensus model about the features of effective management strategies for anxiety in children and young people with LD and autism.

### **Abstract**

We developed interview survey to identify management strategies for anxiety used by parents of children and young people with autism and learning disabilities at home and their teachers at school. A total of 34 participants were interviewed. On average the parents and teachers reported using sixteen different treatments. The number of treatments used varied as a function of the child's age and type/severity of anxiety within the autism spectrum.

Children and young people with LD and autism experience a wide variety of fears and anxiety. According to the screening study for anxiety, the findings indicate that the prevalence of anxiety for this group is 32.6% using Glasgow Anxiety Scale. In terms of how parents and teachers managed their children anxiety, 34 parents and teachers interviewed. Talking and explaining strategy is the most common strategy has been used by up to 50% of parents and teachers, followed by distraction 47%. Reassurance 29.4 % and cuddling 23.5 % are other popular strategies often used by parents more than teachers. Visual schedule is 41 %, this was probably used by most teachers at the class room. Physical activities include swimming, karate, horse riding, walk, and jumping 29.4%, relaxation techniques include using calming music and breathing technique 29.4 %, have a little fun 14.7%, grading anxiety 11.7%, Stop thinking (8.8%), flooding (2.9%), and other strategies for instance rewarding 8.8% / reinforcing 2.9%, and remove physically from the situation 2.9% (Table 1)

Table 1 Rank orders in terms of number / percentage of management strategies used by parents and teachers

Management strategy	Number (N=34)	Percentage of use
1. Talking/ explaining	17	50 %
2. Distraction	16	47 %
3. Visual schedule	14	41 %
4. Reassurance	10	29.4 %
5. Physical activities	10	29.4 %
6. Relaxation techniques	10	29.4 %
7. Time-out	8	23.5 %
8. Cuddling	8	23.5 %
9. Have a little fun	5	14.7 %
10. Grading anxiety	4	11.7 %
11. Remove physically of the situation	4	11.7 %
12. Rewarding	3	8.8 %
13. Stop thinking	3	8.8 %
14. Reinforcing	1	2.9 %
15. Flooding	1	2.9 %
16. Massage	1	2.9 %

## Aim of the various management strategies

### 1. Proactive strategies

Preventing trigger anxiety, e.g., talking in advance / explaining / Build visual schedule, Cuddling / reassurance

### 2. reactive strategies 2.1. Support the child before escalating up its level

Cuddling / reassurance, remove physically from the situation, divertive and distractive strategies, Stop thoughts, grading anxiety. Relaxation techniques such as using music or breathing technique, Physical activities, Humour, time- out, Have a little fun, Flooding.

### 2.2. Manage high level of anxiety

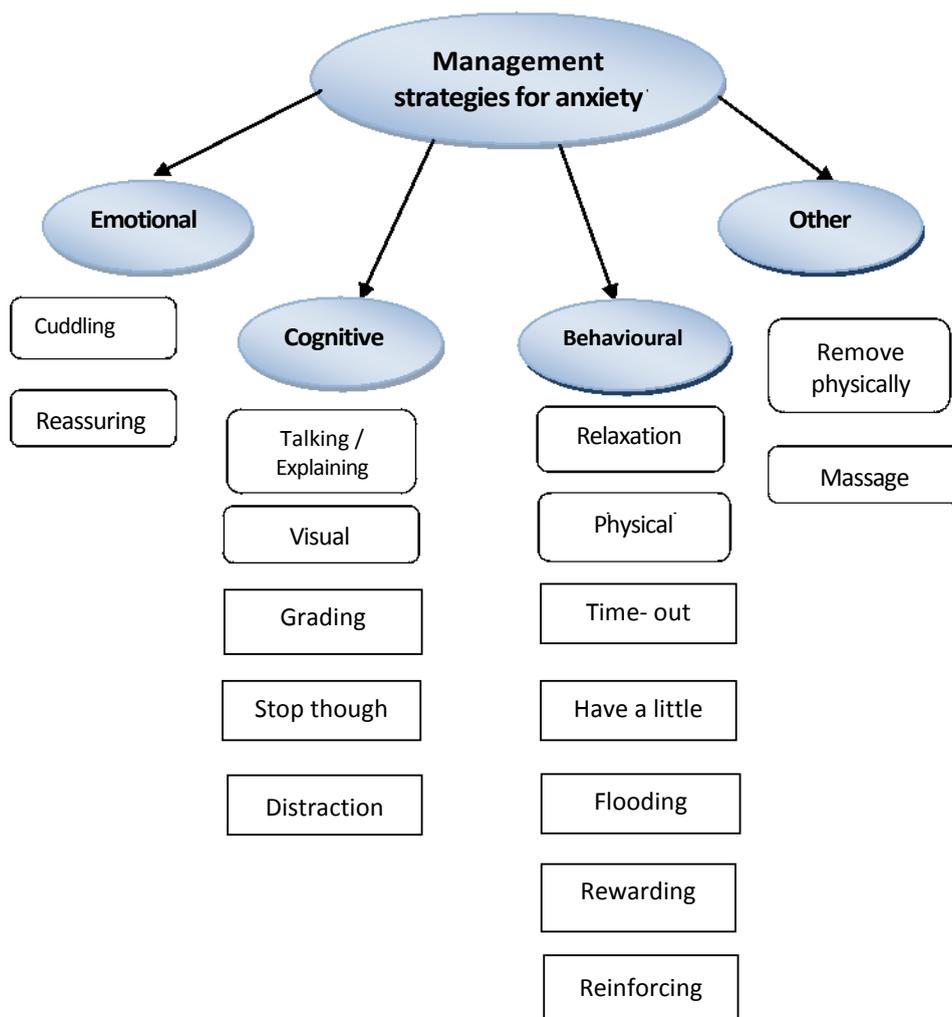
e.g., Time- out, Stop thought, practicing sports, reinforcing, rewarding, Divertive / Distractive.

It is important that parent and teachers understand how the autistic child behave and its autistic features in order to support and help their son / daughter to cope with his / her anxiety.

In addition to this should be done alongside professionals“ health team who also have the appropriate skills to work with the young person and their parents or carers. The ultimate aim is to help children and young people with autism and LD to cope and manage their anxiety and achieve their full potential in terms of ability and emotional well-beinThere is some research evidence concerning the efficacy of most of those management strategies for a range of mental health disorders including anxiety disorders for people with autism or LD. **Behavioural intervention** such as *relaxation* (Green et al. 2006; Bishop 2004; Morrison & Lindsay 1997; Lindsay et al, 1989; Lindsay & Baty 1986) appears to be effective in reducing anxiety. Further more *Physical activities* have been used for different disorders (Chien-Yu Pan & Frey 2006; Chiu Mei 2003; Elliott et al. 1994; Kern et al. 1984). *Visual schedule* is a familiar treatment strategy used by parents of children with autism (Green et al. 2006)

Existing evidence of research studies have demonstrated the potential feasibility of **cognitive behaviour therapy** in reducing anxiety amongst people with learning disabilities and autism (Dagnan and Jahoda 2006; Dagnan 2004; Chalfant et al. 2006; Sofronoff et al. 2005; Joyce and Hardy 2003; Lindsay, et al. 1997)

**Figure 1: management strategies model parents and teachers used.**



### Evaluation of management strategies

Name:

Position:

Date:

Please rate how effective, from your experience, you feel the following strategies are in reducing/managing anxiety in young people with learning disabilities (LD) and autism spectrum disorders (ASD). NB you may not have had direct experience with some of the strategies, but please rate them for how effective you would expect it to be, based on your knowledge of young people with ASD.

Please tick the appropriate number from 1 (the least effective) to 5 (the most effective) on the basis of your experience and understanding of children with ASD and LD.

Strategy	Percentage	1	2	3	4	5
1. Talking/ explaining	50 %	<input type="checkbox"/>				
2. Distraction	47 %	<input type="checkbox"/>				
3. Visual schedule	41 %	<input type="checkbox"/>				
4. Reassurance	29.4 %	<input type="checkbox"/>				
5. Physical activities	29.4 %	<input type="checkbox"/>				
6. Relaxation techniques	29.4 %	<input type="checkbox"/>				
7. Time-out	23.5 %	<input type="checkbox"/>				
8. Cuddling	23.5 %	<input type="checkbox"/>				
9. Have a little fun	14.7 %	<input type="checkbox"/>				
10. Grading anxiety	11.7 %	<input type="checkbox"/>				
11. Remove physically of the situation	11.7 %	<input type="checkbox"/>				
12. Rewarding	8.8 %	<input type="checkbox"/>				
13. Stop thinking	8.8 %	<input type="checkbox"/>				
14. Reinforcing	2.9 %	<input type="checkbox"/>				
15. Flooding	2.9 %	<input type="checkbox"/>				
16. Massage	2.9 %	<input type="checkbox"/>				

**Thank you for helping us with our study!**

## Appendix - X

### Focus group schedule

**Moderator: Ereny Gobrial**

**Date: Sep. 2008**

**Time from:**

**to:**

**Numbers of parents: (     )**

Parents Names:

- 1.
- 2.
- 3.
- 4.

Hello, I am Ereny, the researcher from University of Northumbria. I am doing PhD on intervention and management Strategies for anxiety on children / young people with autism and Learning disabilities.

Can every one please introduce herself, and then we will have a coffee & tea for 10 minutes. To be informed that we will have another break for 15 min. In the middle of the meeting (say after 40 minutes) then we will continue or discussion. Please feel free to interrupt me at any time if you feel tired, or are not able to carry on.

Welcome and refreshment

Let's make start: Thank you for being willing to take part in the pilot study, and this focus group today. As you remember I asked for your permission to tape record the discussion today, so do you mind if I tap- record the interview, once I transcribe the interview, the tap will be destroyed. It will not be used for any other purpose. *Just to let you know that everything we say in this room anonymous and confidential and private.*

Again, I'd like to assure you about the confidentiality, the transcript will not contain any records of your names and all the information you provide, and your son assessments you completed before and after the programme, will be kept in locked storage and destroyed at the end of the study. Your name will not be written on any of these items, and your name will not appear in any reports or documents resulting from this study. The taped discussion from your focus groups and the typed-up versions of these discussions will be kept in locked storage. Please feel free to stop the discussion any time you choose

I would like to talk to you today about your experiences of using these anxiety management strategies with your son/ daughter and how this has affected your child.

1. I would like to discuss with you experience of using these strategies. As you know the strategies presented three categories underneath: Red, Amber, and Green, the Green is a preventing one to avoid your child being nervous. While the Amber is the first

indicator for the anxiety as a self management strategy. While the red refers to this kind of support you may need if your son expressed his anxiety.

Let us start with the daily life strategies (green light): **Visual schedule, Talking and explaining, Regular physical activities, Relaxation.**

**Is anybody used any of these strategies? Well can you tell me please?**

How did you use these strategies? P..... How often do you use then (daily or weekly)? What did you find out of using any of these? P.....

What about other strategies!! (for example Physical activities, what kind of activities? And so....

P.....

Strategy	Implementation	How often use?		Effectiveness	How many parent used this?
		Daily	weekly		
1. Visual –schedule					
2. Talking & explaining					
3. Physical activities					
4. Relaxation					

Which of these strategies did you use most often?

P.....

2. Let us move to the amber strategies (communicating with your child)

**Thermometer approach**

Again, how did you implement this approach? How many times you used it? Have you found this thermometer effective in communicating with your child?

Strategy	Implementation	How often use?		Effectiveness	How many parent used this?
		Daily	Weekly		
5.Thermometer: Picture"s cards Number " s					

Did the card"s numbers or the pictures help your son to express his fears or worries? How?

Was it good to help your child manage his worries or fears? Or at least stop escalating his anxiety?

P. ....  
 .....

3. Thirdly, turn to the red light strategies: we have here 4 strategies: **Have a little fun, distraction, time out and Comfort strategy.**

Which one of these you found more positive on helping your child to manage his anxiety?

How did you implement each one of these strategies? Again, how many times you used? And what is its effectiveness?

P. ....  
 .....

Strategy	Implementation	How often use?		Effectiveness	How many parent used this?
		Daily	Weekly		
6. Have a little fun					
7. Distractive					
8. Time- out					
9. Comfort strategies: reassurance 10. Cuddling					

Which of these strategies did you use most often?

.....  
 .....

**Overall the strategies**

Well, now we finished our talk about the strategies you used, I would like to ask you about overall the program.

4. What is strategy do you think was more effective for dealing with your son"s/ daughter"s anxiety?

P. ....  
 .....

5. Which strategy have you not used? Why?

P. ....  
 .....

6. Do you think you will need to carry out any of these strategies in the future? Which one? And for how long you need to carry it out?

P-----  
-----

7. Have you made any changes or adapted any other strategies and used it to manage your child's anxiety?

P-----  
-----

8. Most of parents seeing their children happier. Can you list the changes you have seen in your son / daughter before and after using management strategies for anxiety disorder?

- 4) .....
- 5) .....
- 6) .....

9. Can I ask you please from your experience which tips that helped you to manage your child's anxiety well? How did you succeed in helping your son? One of these tips (*point to the tips in the information booklet*)? How?

P-----  
-----

10. Can I ask whether your partner used the strategies and how did that work out within the family?

P-----  
-----

11. From your point of view as parent what do you recommend this program to other parent who seeks help?

P-----  
-----

12. Please suggest any improvements, not mentioned above, that could be made to the anxiety management booklet.

(or) What additional information would you like to see included on the parent's booklet?

For example do you think it is helpful to add more information about autism and children characters?

P-----  
-----

Can I finally ask you if you think there is any aspect of your experience of looking for treating / managing anxiety that has not been covered in this group discussion?

***Thank you very much for helping us and giving up your time.***

## Appendix - XI

### CUT-OFF POINT FOR REISS SCALES

Measure	Cut-off
<b>PSYCHOMETRIC SCALES</b>	
Anger/Self-Control	6.0
Anxiety Disorders	5.0
Attention-Deficit	6.0
Autism/ Pervasive	5.0
Conduct Disorder	5.0
Depression	5.0
Poor Self-esteem	6.0
Psychosis	5.0
Somatoform Behaviour	5.0
Withdrawn/ Isolated	6.0
<b>OTHER SIGNIFICANT BEHAVIOUR<sup>1</sup></b>	
Crying spells	1.5
Enuresis	1.5
Hallucinations	1.5
Involuntary Motor movement	1.5
Lies	1.5
Obese	1.5
Pica	1.5
Sets Fires	1.5
Sexual problem	1.5
Verbally Abusive	1.5
<b>TOTAL SCORE (SEVERITY)</b>	<b>29.0</b>

<sup>1</sup> The suggested cutoff points for other Significant Behaviour items are not considered when determining positive or negative results for dual diagnosis

## Appendix - XII

# Calm Child Programme

## Anxiety management strategies- Parent Information



**For further information contact:**

Researcher: Ereny Gobrial

Email: [Ereny.gobrial@unn.ac.uk](mailto:Ereny.gobrial@unn.ac.uk)

Research Supervisor: Dr Raghu Raghavan

Email: [raghu.raghavan@unn.ac.uk](mailto:raghu.raghavan@unn.ac.uk)

**Thanks for helping us with our study!**

Dear Parent

You are being asked to agree to take part in our study. This information sheet is designed to help you to support your child to cope better with anxiety. We have been studying the different ways parents and teachers support children and young people to help to manage their anxiety. We have gathered positive strategies from parents and teachers and discussed these with health professionals. We have now developed a set of strategies that parents, teachers and health professionals may find useful in helping children and young people with autism to cope with anxiety.



---

---

**How parents can use this information sheet**

---

---



This booklet provides you with some useful information and positive management strategies to deal with your child's fears and worries (anxiety).

I would like you to use these strategies for 3 months with your child. Please monitor your child each week and provide a brief report about using these ideas and whether it was helpful in the diary provided (see attached diary).

**What will happen next?**

I need your feedback about using this information. You will have your own thoughts about how it works for your child. After you have used these strategies for 3 months, I will organise a discussion with you and the other parents who took part in this study to see the usefulness of these strategies. Confidentiality will be respected. I will be available to answer any questions in relation to the interventions specified in the information booklet.

Yes. All the information you provided, and your assessments you completed before

**Will my taking part in this study be kept confidential?**

and after the programme will be kept in locked storage and destroyed at the end of **What will happen to next?**

the study, in line with the Data Protection Act (1998). Your name will not be written on any of these items, and your name will not appear in any reports or documents resulting from this study.

## **What do you know about autism, learning disabilities, and anxiety?**

### **Child with autism shows three types of symptoms:**

- ✚ Impaired social interaction;
- ✚ Problems with verbal and nonverbal communication and imagination; and
- ✚ Unusual or severely limited activities and interests.

### **Learning Disability includes the presence of:**

- ✚ A significantly reduced ability to understand new or complex information, to learn new skills (Impaired intelligence), with;
- ✚ A reduced ability to cope independently (impaired social functioning);
- ✚ Which started before adulthood, with a lasting effect on development?

### **Anxiety: what is that?**

All children experience some anxiety; this is normal and expected, but when it interrupts a child's normal activities like attending school and making friends or sleeping, and has a bad impact on overall his adaptation behaviour, such anxiety becomes a problem.

## **How do children with ASD show anxiety?**

Children and young people with autism experience a wide variety of fears and anxiety.

### **Children are all different**

- Child might feel very hot or sweaty.
- Child may cry a lot.
- Child may shake hands and legs.
- Child might feel breathless.
- Child might find it is difficult to sit still.
- Child might feel panicky.
- Child's stomach might feel funny.



### **Children with autism also feel worried or nervous in different ways**

Here are some words that children with autism and learning disability use to explain their fears and worries:

- Stressed
- Things wrong with me
- Fed up
- In a huff
- Frightened
- Temper

### **What can cause anxiety?**

There are lots of reasons why children and young people may be at risk of getting nervous:

- When you change his/ her daily routine
- When s/he meets new people
- When someone comes to your house
- When he/ she is in busy – crowded places
- Facing new or un-expected situations
- Feelings /worries about family, future, and his mental health.
- Difficulties in understanding the world and in communicating with others.
- Not being able to communicate what s/he wants to say.

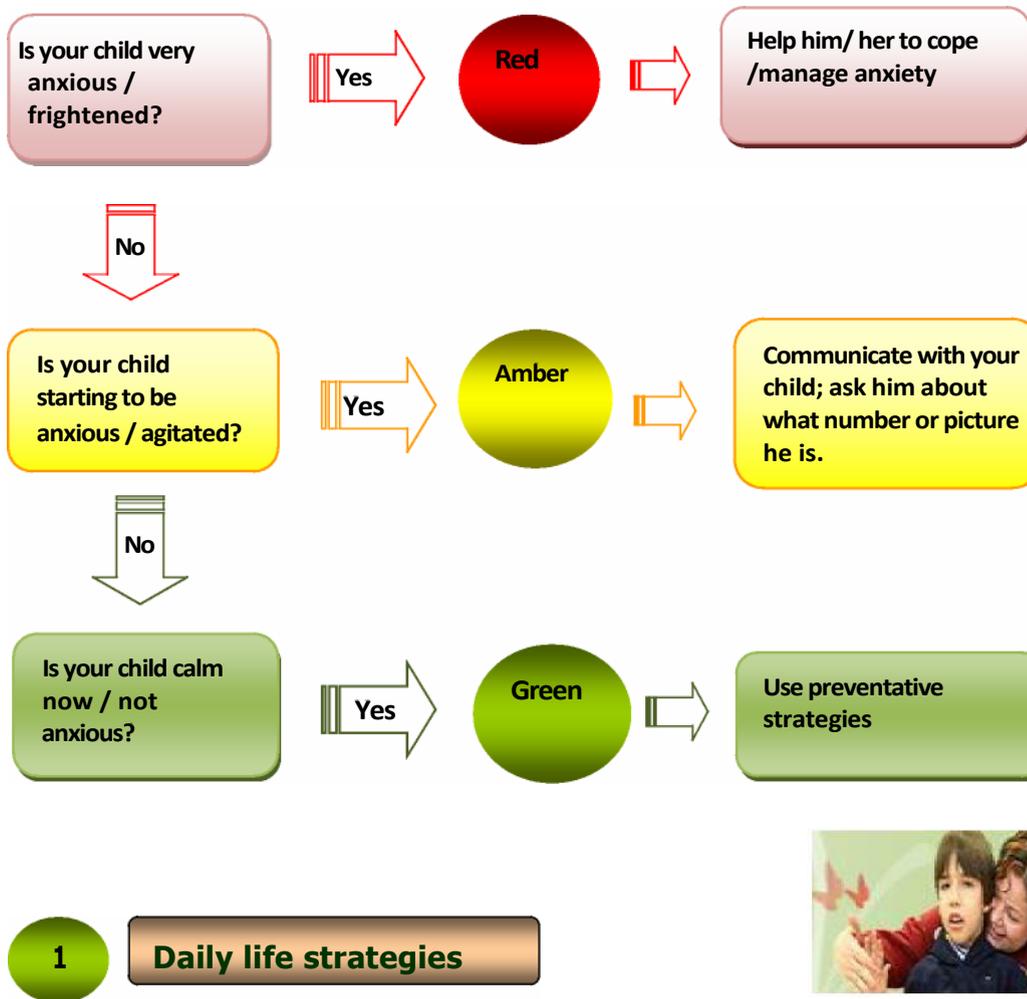
### **What are anxiety management strategies?**

Anxiety management strategies involve techniques that parents and teachers can use to help children with autism and learning disability to cope better with their worries and fears. This information sheet shows you some management strategies that parents and teachers think are useful for managing anxiety in children and young people with autism. Professionals such as psychiatrists, psychologists, nurses and social workers have also seen these strategies and think they could be useful.

### **Here are the recommended positive strategies which could help you to help your child manage his anxiety**

We operate a “traffic light” system to determine your child’s anxiety level and how you help her/him to cope with in each level. In the following three sections you will find a traffic system: we will go ahead with the GREEN colour that refers to strategies you might use most of the time when your child is OK, then the AMBER, which means strategies you might use once you notice your son’s anxiety, and giving you what level of anxiety he is. Finally, the RED colour you should use when he is anxious (Figure 3).

**Figure 3: Traffic light systems**



The Green light strategy is a proactive approach which aims at crisis prevention. The focus is on supporting your child to remain calm and for you to be one step ahead. You might need to use these ideas most of the time, day by day in order to reduce your child's anxiety.

**Here are some recommended ideas:**

**Visual schedule:**

The visual schedule or time table uses pictures as a means to support your child to cope with change. Children with autism are more sensitive to any change in their daily routine. So this visual time table helps to reduce anxiety because it helps them to understand what they are



going to do during their day. A visual timetable makes time concrete, allows a child to see time passing, and to see plans for the future.

For most children, arrange the timetable from left to right. For some young children, a top to bottom format may be more understandable.

Examples:



(See attached file for more pictures)

### **Talking and explaining:**

Talk to your child in a very simple language constantly about what he is going to do. Keep the information very simple. Talk over and over again about the situation and let your child know what is happening, from A to X, Y and Z. For example we are now eating a snack, and then in 5 minutes we will play. In 1/2 hour we will put on our coat and shoes on and we will get in the car. The basic rule is to be clear, concise, and consistent.

Also explain in advance any out of routine events, like holidays using brochures and leaflets for the place you are going to visit, as a trip with the school, or school shopping trips.

### **Regular physical activities:**

-  Physical activity is very good for your son/ daughter particularly if they are very agitated. Activities that other parents have found helpful are:
  -  Get outside and do some exercise, such as running in the garden, swinging.
  -  Going for a walk, a short walk in the fresh air can be helping him feel good, or perhaps for a long walk with the dog.
- Jumping on a trampoline.

- + Special regular activities: e.g. swimming, Karate, riding horse, football, dancing.

## + **Relaxation**

Help your child to relax. Firstly it is important to create a relaxing environment - choose a comfortable, quiet and peaceful room. It may be possible to teach your child how to relax as a coping skill when he becomes agitated or angry. There are many ways to help him to relax including:

### + *Breathing technique:*

For example deep breathing, to take time to breathe slowly and deeply and count 1 to 10, as this can help them to feel calm. Also practice some breathing exercise, for example, ask your child to pretend that he is blowing a balloon and then let the balloon out.

### + *Listening to relaxing music:*

Music can stimulate and develop more meaningful and playful communication in people with autism. Music can also play an important role for children with autism in developing positive interactions. For example you can use calming music every time before bedtime.

- + *Read books* e.g., book explaining to the child how s/he can express their feeling.

- + Warm bath in low lighting: may help your child to feel calmer.

2

## **Communication with your child's anxiety!**

It is essential to talk to the child and to gain his/her view of the situation. Children may be able describe their fears or anxiety and the situations which give rise to them. This communication is likely to be helpful. If you noticed your son / daughter appeared worried or agitated, then there is an opportunity to start to communicate with him/ her. So you might tell him that you notice he looks anxious. For example, "Are you alright?" Or "How do you feel?"

*Here are some ways to help your child to tell you more*

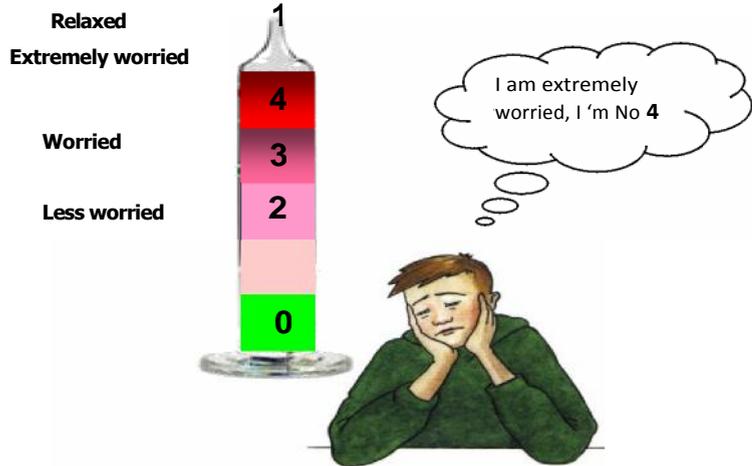
**Thermometer approach**

You may present the thermometer of anxiety rating scale to the child and ask him to let you know which number he is.

E.g. How worried are you? Can you show me? Are you a 2 or a 3?

**Figure 4:**

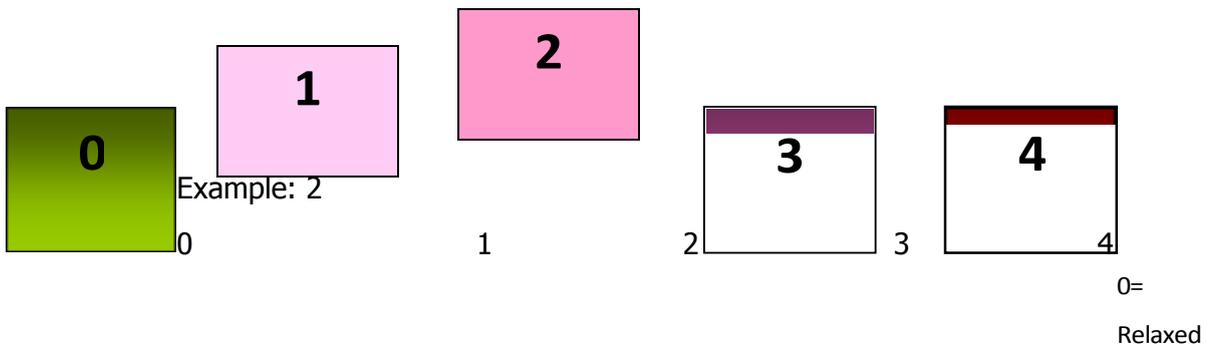
**Anxiety -Scale Thermometer**



**Anxiety pictures/ Numbers**

You can also use pictures to help your child tell you about their feelings. You might ask your child to draw pictures that make sense to them.

Example: 1



**Have a little fun**

Having fun is a great way to increase good feeling and release tension. Getting in touch with fun and play is often easier for children than for adolescents. Sharing fun with your son/ daughter is often helpful to release his fears or worries, for example,

play his favourite games, try some painting. Children can express their feeling by drawing.

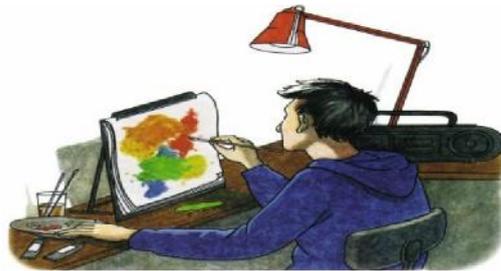
3

### Reactive strategies

When your child or young person is agitated or feeling anxious, there are a number of ways to help them to cope with anxiety.

#### + Special interest (distraction)

One way of helping your child to cope with his anxiety is to make use of his particular interest. When you find your son/ daughter agitated ignore the situation and try to distract him before escalating his anxiety level. The trick here is to let him/her do something he enjoys e.g., watching his favourites DVDs, playing favourite games, jumping, drawing, feeding the birds, his favourite toy.



e.g., it was (good) to distract (child) by watching videos, he was really extremely calm, you can easy pick him up." Mum

#### Time- out



Time out gives your child the chance to have time to manage themselves. This gives him the chance to calm down. The time given should be kept to 1 minute for each year of age although this can be repeated. A quiet stimulation-free spot is a good choice. Some children ask for time-out for themselves.

e.g." the best thing is to keep him away, after a while; 20-30 minutes, this calms him down- as though nothing happened" Mum

#### Comfort strategy (reassurance & cuddling)



Parents can offer physical expressions of love for their child to help to calm them down. Simply placing your hands on the back or holding hands can be very relaxing. You will know what areas are most sensitive for your child and so avoid them. You may need to find out what sort of touch or holding gives most comfort.

## **Top tips that will help**

1. Calm yourself down, be patient and don't shout: You will have to be very calm and patient.
2. Usually try to prevent circumstances that may trigger anxiety. E.g. avoid what gets him worried as much as you can.
3. You might try to be more firm as a way of taking control
4. Get your son or daughter more comfortable: find out what gets him/ her happy.
5. Understanding autistic characters, and understanding your child's anxiety. For instance: try to go to his world not ask him to come into yours.
6. Change your behaviour to accommodate the needs of your child with autism.
7. Distract the child before escalating his anxiety
8. Try different approaches "you may need different things from time to time"  
Mum
9. Try to keep 1 step ahead.
10. Keep the information very, very simple.
11. It is important not to force something the child does not want, and it is also important not to take it to heart if a particular approach does not go as you expected.

By the end of this program, if your child is becoming less anxious, then you can stop some strategies, while you might still need to use some for a longer time.



I Hope this information gives you practical ideas to help your son / daughter cope with his/ her anxiety, fears and worries and make daily life much calmer.

**NB** It is important to realize that each child with autism is different so the descriptions in this information sheet should only be taken as a general guide.

**Appendix – XIII**  
**PARENT’S INVITATION LETTER 2**



Dear Parent

I am a research student at the University of Northumbria (I was at University of Bradford and recently moved to University of Northumbria). I am doing a project on the help, support and management of children / young people with autism, who have learning disabilities and anxiety. Parents play an important part in helping/ supporting the young person to cope with their anxiety and general coping in their life.

Anxiety is a common problem for children and young people with autism and learning disability. Parents play an important part in helping son/ daughter to cope with his/ her anxiety.

I interviewed about 34 parents and teachers (in Bradford) of children with autism and learning disabilities last year. It involved the types of management strategies that they use with their son/ daughter. Building on this knowledge, I am doing a small study with parents on information about anxiety management strategies.

The plan is to provide you with information about the most useful management strategies for children with autism and learning disabilities. I would like you to use this information with your son/ daughter for up to 3 months and then. I will organise a focus group in relation to the usefulness of these strategies.

This information sheet has been discussed with professionals such as psychiatrists, psychologists, nurses and social workers in Bradford. This project has been approved by Bradford local research ethics committee (REC reference no. 06/Q1202/45) All information from this study will be anonymous and confidential and will only be used for the purpose of the project.

I would very much appreciate your involvement in this study and would therefore be grateful if you could contact me either call, email or post me. If you require any more information regarding to this project I can be contacted on 0191 2421482 / 07703002414; [Email: ereny.gobrial@unn.ac.uk](mailto:ereny.gobrial@unn.ac.uk)

Thank you

**Ereny Gobrial**

-----  
*U I would like to be involved on, and would like more information about the project, please contact me.*  
*U I would not like to be involved in the project. Please do not contact me.*

Name of parent / carer \_\_\_\_\_

Child name \_\_\_\_\_ Age \_\_\_\_\_

Telephone \_\_\_\_\_ Email: \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

**Contact for further information**  
Researcher: Ereny Gobrial, Tel: 0191 2421482;  
[email: Ereny.gobrial@unn.ac.uk](mailto:ereny.gobrial@unn.ac.uk)

## Appendix – XIV

### PARENT'S INFORMATION LEAFLET



#### **Exploration of interventions and management strategies for anxiety in young people with autism and learning disabilities**

##### **Parent Information Sheet**

You are being asked to agree to take part in our study. Before you decide it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve. Reading this leaflet, discussing it with others and asking us any questions you might have will help you decide whether or not you would like to take part.

##### **What is the purpose of the study?**

This study is looking at kinds of management strategies used by parents to help their son/ daughter to cope with anxiety.

##### **Why have I been chosen?**

Because you are a parent with a child or a young person with autism.

##### **Do I have to take part?**

No. It is up to you whether you would like to take part. We are giving you this information sheet to help you make that decision. If you do decide to take part, remember that you can stop being involved in the study whenever you choose, without giving a reason.

##### **What will happen if I take part?**

- ✚ The information package for the anxiety management programme will be posted to you. After a few days of receiving the information, the researcher will contact you to be sure that you have received and read the information.
- ✚ You will be asked to complete the consent form, Glasgow anxiety scale and post them in the attached self addressed envelope.
- ✚ You will be asked to read over the information sheet and start to use the strategies with your child.
- ✚ We will also ask you to monitor your child's anxiety and describe it every week in the diary provided.
- ✚ The researcher will contact you on every fortnight to see how you are getting on. And she will be available to answer any questions in relation to the interventions specified in the information booklet.

- ✦ Please feel free to contact me at any time if you have any concerns about the interventions and strategies you have chosen to adopt, and I will be happy to answer any question.
- ✦ After the 13 weeks, we will ask you to complete the Glasgow anxiety scale again. We
- ✦ will then invite you to take part in a focus group to discuss the effectiveness of using these management strategies with your child.
- ✦ The focus group would happen after the 13<sup>th</sup> week of the programme, it will be arranged for a convenient date and location for everyone taking part. With the group's permission, the researcher would record this focus group on audiotape, to make sure she remembers everything you talk about. What you say during the focus group will be kept confidential and anonymous, and this is explained in more detail in a later section of this information sheet.

### **What are the possible disadvantages of taking part?**

You will be asked to give up some of your time to take part in the study and up to one hour at the end of the programme for the focus group with the researcher to discuss the results of using these anxiety management strategies. However, you are able to withdraw from the study at any point without giving a reason. In the focus group you will be asked about your experiences of using these anxiety management strategies with your son/daughter and how this has affected your child. Talking about our lives can sometimes be upsetting. The researcher will stop the discussion if anyone becomes upset. You can also stop the discussion any time you choose. The researcher is experienced at talking to parents with children with autism and learning disabilities.

### **What are the possible benefits of taking part?**

There may be a benefit for you and your child from taking part in the study. By practising different types of management strategies with your child, you may be able to help him to cope with his worries and fears.

### **Will my taking part in this study be kept confidential?**

Yes. All the information you provided, and your assessments you completed before and after the programme, will be kept in locked storage and destroyed at the end of the study, in line with the Data Protection Act (1998). Your name will not be written on any of these items, and your name will not appear in any reports or documents resulting from this study. The taped discussion from your focus groups and the typed-up versions of these discussions will be kept in locked storage.

### **What will happen to the results of the study?**

The result will be included in the PhD thesis, any publications from the research, and feedback to parents, teachers and carers participating in the study. Feedback will be to the special schools, social services, through newsletters, as well as NAS - through NAS newsletter. The findings may also share with the Learning disability research group at the school, University's seminars.

### **Who is organizing and funding the study?**

The researcher is carrying out this study as part of her PhD research at Northumbria University, the researcher is funded by the Egyptian Government.

### **Who has reviewed the study?**

Before we could begin this study, we had to obtain permission from the Ethics Committee at Northumbria University. The Committee reviewed the way we were planning to conduct the study in order to safeguard your interests.

**Contact for further information:**

Researcher: Ereny Gobrial, Tel:0191 2156703

[Email: Ereny.gobrial@unn.ac.uk](mailto:Ereny.gobrial@unn.ac.uk)

Research Supervisor: Dr Raghu Raghavan, Tel: 191 2156093

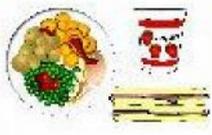
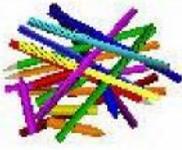
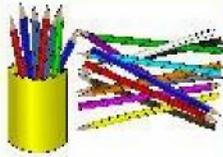
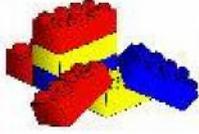
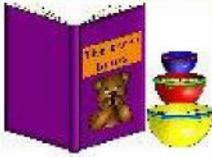
**Appendix . XVI**  
**GLASGOW ANXIETY SCALE (GAS-ID)**





Appendix . XVII

**VISUAL TIMETABLE (EXAMPLES)**

 <p>Lunch time</p>	 <p>Colouring</p>	 <p>Cooking</p>	 <p>Snack time</p>	
 <p>Register</p>	 <p>Drawing</p>	 <p>Painting</p>	 <p>Building bricks</p>	
 <p>Computer</p>	 <p>Music</p>	 <p>Singing</p>	 <p>Puzzles</p>	
 <p>Story time</p>	 <p>Tidy time</p>	 <p>Puppets</p>	 <p>Home time</p>	
 <p>Reading</p>	 <p>Plasticine</p>	 <p>Reading</p>	 <p>Making</p>	
 <p>Cars</p>	 <p>Sand</p>	 <p>Choosing</p>	 <p>Water</p>	
 <p>Snack time</p>	 <p>Story time</p>	 <p>Swimming</p>	 <p>Topic</p>	 <p>Visitor</p>

## Appendix . XIX

### Parent"s monitoring diary

Case No.

Date:

#### Week 1

Week 1	Management strategy/ How many times?	Anxiety level			Positive point	Negative point
		0	1	2		
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

Parent"s overall rating for the first week:

-----  
 -----

For the anxiety level 0=----- 1=----- 2=-----

## Appendix – XX

### PARENT’S EVALUATION SHEET



#### Calm Child Programme Evaluation Sheet

I.D No

Date:

Thank you for taking part in the study and using the anxiety management programme with your child. We would now like to know what you thought of the programme.

#### 1. About you and your child

Your child’s

age Your age:  16 - 24  25 - 34  35 - 49  50 - 64  65 +

Your child

attends:  Mainstream School  Residential School

Special school

#### 2. About the strategies

Please rate how effective, from your experience, you feel the strategies were in reducing/managing your child’s anxiety. Please tick the appropriate number from 1 (the least effective) to 5 (the most effective) at helping you to reduce anxiety for your son/ daughter.

<b>Strategy</b>		<b>1 Not effective</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5 Extremely effective</b>
<b>Green</b>	Visual time-table					
	Talking & explaining					
	Physical activities					
	Relaxation					
<b>Amber</b>	Thermometer					
<b>Red</b>	Have a little fun					
	Distraction					
	Time-out					
	Reassurance					
	Cuddling					

**4. Please use  $\checkmark$  or X to indicate whether the following tips helped you to manage your child's anxiety or not:**

- Calm yourself down, be patient and don't shout: You will have to be very calm and patient.
- Usually try to prevent circumstances that may trigger anxiety. E.g. avoid what gets him worried as much as you can.
- You might try to be more firm as a way of taking control.
- Get your son or daughter more comfortable: find out what gets him/ her happy.
- Understanding autistic characters, and understanding your child's anxiety. For instance: try to go to his world not ask him to come into yours.
- Change your behaviour to accommodate the needs of your child with autism.
- Distract the child before escalating his anxiety
- Try different approaches "you may need different things from time to time"
- Try to keep 1 step ahead.
- Keep the information very, very simple.
- It is important not to force something the child does not want, and it is also important not to take it to heart if a particular approach does not go as you expected.

**4. Overall, the information booklet:**

1) How well did the information booklet of management strategies help the child's anxiety management? (Please circle)

*Not very well*

*Very well*

1                      2                      3                      4                      5

2) How was the content of the information booklet: (please circle) *Poor*

*Acceptable*

*Good*

*Very good*

*Excellent*

1                      2                      3                      4                      5

3) How easy was it to use the information booklet? *1= Not easy 5= Very easy*

1                      2                      3                      4                      5

4) Was the time span of the programme : ( please circle)

*Too short*

*Just right*

*Too long*

5) How well does the information booklet meet your expectations to help your child?

*1= not very well*

*5= very well*

1                      2                      3                      4                      5

6) What were the most useful strategies you found with your son! daughter?  
-----  
-----

7) Which of those strategies did you use most often?  
-----  
-----

8) What was the least useful strategy?  
-----  
-----

9) After how many weeks you did notice any changes on your son! daughter?  
(Please circle)

**3 weeks**

**6 weeks**

**12 week**

**Other** (pleas indicate) -----

10) How likely are you to recommend this programme to someone else?

**1= not very likely**

**5= very likely**

**1**

**2**

**3**

**4**

**5**

11) Please suggest any improvements, not mentioned above, that could be made to the anxiety management booklet.

-----  
-----  
-----  
-----

**Thank you very much for your cooperation**