AN EVALUATION OF THE AUTISM, EMOTIONAL WELL-BEING AND ADOLESCENCE PROGRAMME; A LOCALLY DEVELOPED PSYCHOEDUCATION INTERVENTION FOR PARENTS OF YOUNG PEOPLE WITH AUTISM.

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TABLE OF CONTENTS

LIST OF TABLES VIII

LIST OF FIGURES X

LIST OF APPENDICIES XI

GLOSSARY OF ABBREVIATIONS XIII

ABSTRACT XIV

CHAPTER 1 – INTRODUCTION 1

1.1 CONTEXT FOR THE RESEARCH 1
1.2 FOCUS OF THE RESEARCH THESIS AND ITS UNIQUE CONTRIBUTION 1
1.3 THE RESEARCHER'S PROFESSIONAL AND PERSONAL INTEREST IN THE RESEARCH TOPIC 2
1.3 STAKEHOLDER INVOLVEMENT 2
1.4 STRUCTURE OF THE RESEARCH THESIS 3

CHAPTER 2 - REVIEW OF LITERATURE 4

2.1 INTRODUCTION TO THE CHAPTER 4
2.2 AUTISM 5
2.2.1 DEFINITIONS OF AUTISM SPECTRUM DISORDER 5
2.2.2 TERMINOLOGY 6
2.2.3 DIAGNOSIS OF AUTISM 6
2.2.4 PREVALENCE OF AUTISM 7
2.2.5 THE IMPACT OF AUTISM 7
2.2.6 AUTISM AND RESEARCH IN THE UK 8
2.2.7 SUMMARY 9
2.3 EMOTIONAL WELL-BEING AND MENTAL HEALTH 10
2.3.1 DEFINITION OF EMOTIONAL WELL-BEING 10
2.3.2 EMOTIONAL WELL-BEING AND MENTAL HEALTH IN CHILDREN AND YOUNG PEOPLE 10
2.3.3 IMPORTANCE OF EMOTIONAL WELL-BEING 11
2.3.4 APPROACHES TO PROMOTE EMOTIONAL WELL-BEING 11
2.3.5 EMOTIONAL WELL-BEING IN CHILDREN AND YOUNG PEOPLE WITH AUTISM 14
2.3.6 WHY ARE YOUNG PEOPLE WITH AUTISM EXPERIENCE POORER MENTAL HEALTH OUTCOMES 15
2.3.7 APPROACHES TO PROMOTE EMOTIONAL WELL-BEING IN CHILDREN AND YOUNG PEOPLE WITH AUTISM 16
2.3.8 SUMMARY 17
2.4 ADOLESCENCE 19
2.4.1 DEFINITION OF ADOLESCENCE 19
2.4.2 ADOLESCENCE AND AUTISM 19
2.4.3 POSITIVE APPROACHES TO SUPPORT ADOLESCENTS WITH AUTISM 19
2.4.4 AUTISM, SEXUALITY AND RELATIONSHIPS 20
2.4.5 TRANSITION IN ADOLESCENCE FOR INDIVIDUALS WITH AUTISM 21
2.4.6 PROMOTING INDEPENDENCE IN YOUNG PEOPLE WITH AUTISM 22
2.4.7 SUMMARY 23

2.5 PARENT EDUCATION PROGRAMMES 25
2.5.1 DEFINITION OF PARENT EDUCATION 25
2.5.2 PARENT PROGRAMMES AS AN APPROACH TO INTERVENTION 25
2.5.3 RATIONALE FOR PARENT PROGRAMMES 26
2.5.4 ECOLOGICAL SYSTEMS THEORY 26
2.5.5 SOCIAL LEARNING 27
2.5.6 PARENT PROGRAMMES TO PROMOTE CHILDREN AND YOUNG PEOPLE'S WELL-BEING 27
2.5.7 PARENT PROGRAMMES AND AUTISM 29
2.5.8 ELEMENTS SUPPORTING PARENT PROGRAMMES TO BE EFFECTIVE 30
2.5.9 CHANGE PROCESSES IN PARENT PROGRAMMES 31
2.5.10 SUMMARY 34
2.6 REVIEW OF RESEARCH 36
2.6.1 INTRODUCTION TO THE SYSTEMATIC SYNTHESIS OF RESEARCH 36
2.6.2 REVIEW QUESTION 36
2.6.3 PROTOCOL 37
2.6.4 SCREENING THE PAPERS 39
2.6.5 MAP OF THE RESEARCH MEETING THE INCLUSION CRITERIA 42
2.6.6 REVIEW OF THE RESEARCH 46
2.6.7 REVIEW OF OTHER KEY STUDIES IDENTIFIED 48
2.6.8 REFLECTIONS ON THE SEARCH STRATEGY USED TO IDENTIFY RESEARCH 51
2.6.9 SUMMARY 51
2.7 THE RESEARCH 53
2.7.1 RATIONALE FOR THE RESEARCH 53
2.7.2 RESEARCH QUESTIONS 54

CHAPTER 3 - METHODOLOGY **55**

3.1 INTRODUCTION TO THE SECTION 55
3.2 REAL-WORLD RESEARCH AND EVALUATION RESEARCH 55
3.3 RESEARCH PARADIGMS 56
3.3.1 POSITIVISM AND POST-POSITIVISM PARADIGM 57
3.3.2 CONSTRUCTIVISM 58
3.3.3 PRAGMATIC APPROACH 59
3.4 MIXED METHODS 60
3.5 SUMMARY OF THE CHOSEN DESIGN 61
3.6 VALIDITY AND RELIABILITY 62
3.7 ETHICAL CONSIDERATIONS 62
3.8 THE AUTISM, EMOTIONAL WELL-BEING AND ADOLESCENCE PROGRAMME 66
3.8.1 NAME OF THE INTERVENTION 66
3.8.2 RATIONALE FOR THE INTERVENTION 66
3.8.3 MATERIAL USED IN THE DELIVERY OF THE INTERVENTION 67
3.8.4 PROCEDURE FOR INTERVENTION DELIVERY 67
3.8.5 INTERVENTION PROVIDER 71
3.8.6 MODEL OF INTERVENTION DELIVERY 71
3.8.7 LOCATION OF INTERVENTION DELIVERY 71
3.8.8 STRUCTURE OF DELIVERY 71
3.8.9 TAILORING OF THE INTERVENTION 72
3.8.10 FIDELITY OF INTERVENTION DELIVERY 72
3.9 SUMMARY 72

CHAPTER 4 - QUANTITATIVE DESIGN **73**

4.1 INTRODUCTION TO THE SECTION 73
4.2 PARTICIPANTS 73
4.2.1 INCLUSION CRITERIA 73

4.2.2 SAMPLING 73
4.2.3 SAMPLE SIZE 76
4.2.4 DESCRIPTION OF PARTICIPANTS 77
4.3 EXPERIMENTAL CONDITION 81
4.3.1 INTERVENTION DELIVERY 81
4.3.2 INTERVENTION FIDELITY 81
4.3.3 DATA COLLECTION PROCEDURE 82
4.3.4 MEASUREMENT METHODS 82
4.3.4.1 RATIONALE FOR SPECIFICALLY CONSTRUCTING A MEASURE 82
4.3.4.2 DEVELOPING AN INSTRUMENT 83
4.3.4.3 RELIABILITY AND VALIDITY OF THE INSTRUMENT 87
4.4 VALIDITY OF QUANTITATIVE DESIGN 89
4.4.1 INTERNAL VALIDITY 89
4.4.2 EXTERNAL VALIDITY 94
4.5 APPROACH TO STATISTICAL ANALYSIS 94
4.5.1 PARAMETRIC VERSUS NON-PARAMETRIC APPROACHES TO ANALYSIS 94
4.5.2 COMPUTING VARIABLES 95
4.5.3 TREATMENT OF MISSING DATA 95
4.5.4 MANN-WHITNEY U TEST 95
4.5.5 WILCOXON SIGNED RANK TEST 95
4.5.6 STATISTICAL SIGNIFICANCE 96
4.5.7 TYPE I AND TYPE II ERRORS 96
4.5.8 EFFECT SIZE 96
4.6 SUMMARY 98

CHAPTER 5 - QUANTITATIVE RESULTS **99**

5.1 INTRODUCTION TO THE CHAPTER 99
5.2 RESEARCH QUESTION ONE 99
5.2.1 HYPOTHESIS 99
5.2.2 ANALYSIS 100
5.2.3 SUMMARY 103
5.2.4 HYPOTHESIS 104
5.2.5 ANALYSIS 104
5.2.6 SUMMARY 107
5.3 RESEARCH QUESTION TWO 108
5.3.1 HYPOTHESIS 108
5.3.2 ANALYSIS 108
5.3.3 SUMMARY 111
5.3.4 HYPOTHESIS 112
5.3.5 ANALYSIS 112
5.3.6 SUMMARY 115

CHAPTER 6 - QUALITATIVE DESIGN **116**

6.1 INTRODUCTION TO THE CHAPTER 116
6.2 PARTICIPANTS 116
6.2.1 SELECTION OF PARTICIPANTS 116
6.2.2 DESCRIPTION OF PARTICIPANTS FROM WHICH QUALITATIVE DATA WAS COLLECTED 117
6.3 PROCEDURE 119
6.3.1 INTERVENTION 119
6.3.2 APPROACH TO INFORMATION GATHERING 119
6.3.3 APPROACH TO DATA ANALYSIS 119
6.4 ENSURING THE QUALITY OF THE QUANTITATIVE DESIGN 124
6.4.1 CREDIBILITY 124

6.4.2 TRANSFERABILITY 127
6.4.3 DEPENDABILITY 127
6.4.4 CONFIRMABILITY 127

CHAPTER 7 - QUALITATIVE RESULTS **129**

7.1 INTRODUCTION TO THE CHAPTER 129
7.2 THEMATIC RESULTS: PARTICIPANTS' REFLECTIONS OF THEIR EXPERIENCES OF ATTENDING THE AUTISM, EMOTIONAL WELL-BEING AND ADOLESCENCE PROGRAMME. 129
7.2.1 SATISFACTION WITH THE CONTENT OF THE AEWA PROGRAMME 131
7.2.2 LEARNING THROUGH ATTENDING THE AEWA PROGRAMME 132
7.2.3 VALUED COMING TOGETHER WITH OTHER PARENTS OF CHILDREN WITH AUTISM 133
7.2.4 POSITIVE EXPERIENCE ATTENDING THE AEWA PROGRAMME 133
7.2.5 GOOD STRUCTURE OF THE AEWA AND APPROACH TO DELIVERY 134
7.2.6 AREAS FOR DEVELOPING THE AEWA PROGRAMME 135
7.3 THEMATIC RESULTS: PARTICIPANTS' SUBSEQUENT EXPERIENCES AS A RESULT OF ATTENDING THE AUTISM, EMOTIONAL WELL-BEING AND ADOLESCENCE PROGRAMME 137
7.3.1 THE KNOWLEDGE AND UNDERSTANDING GAINED ON AEWA PROGRAMME INFLUENCED THINKING 139
7.3.2 EXPERIENCED A POSITIVE EFFECT ON THEIR AFFECT 140
7.3.3 CHANGE IN BEHAVIOUR 141
7.3.4 CHALLENGES OF IMPLEMENTING STRATEGIES FROM THE PROGRAMME 141
7.3.5 SHARING COURSE INFORMATION WITH OTHERS 142
7.4 SUMMARY 143

CHAPTER 8 – DISCUSSION **144**

8.1 INTRODUCTION TO THE CHAPTER 144
8.2 SUMMARY OF AIMS 144
8.3 DISCUSSION OF FINDINGS 145
8.3.1 RESEARCH QUESTION ONE 145
8.3.2 RESEARCH QUESTION TWO 148
8.3.3 RESEARCH QUESTION THREE 150
8.3.4 RESEARCH QUESTION FOUR 155
8.3.5 AEWA PARENT PROGRAMME AS AN INTERVENTION TO SUPPORT THE PROCESS OF CHANGE 160
8.3.6 SUMMARY OF FINDINGS 165
8.4 METHODOLOGICAL EVALUATION 167
8.4.1 INTRODUCTION TO THE SECTION 167
8.4.2 RESEARCH DESIGN 167
8.4.3 INFERENCE QUALITY 168
8.4.4 CONTENT VALIDITY 169
8.4.5 RELIABILITY 170
8.4.6 EXTERNAL VALIDITY 172
8.5 IMPLICATIONS FOR RESEARCH 174
8.6 IMPLICATIONS FOR PRACTICE 176
8.6.1 IMPLICATIONS FOR PARENTS AND CHILDREN WITH AUTISM 176
8.6.2 IMPLICATIONS FOR EDUCATIONAL PSYCHOLOGISTS 176
8.6.3 IMPLICATIONS FOR LOCAL AUTHORITY AND POLICY 179

CHAPTER 9 - CONCLUSION **180**

9.1 ORIGINAL CONTRIBUTION OF THIS RESEARCH 180
9.2 THE AUTISM, EMOTIONAL WELL-BEING AND ADOLESCENCE PROGRAMME AS AN EFFICACIOUS APPROACH TO INTERVENTION 180
9.3 CONCLUDING SUMMARY 181

REFERENCES **182**

APPENDICES **205**

LIST OF TABLES

Table 2. 1: The search formula for the systematic search or research 38

Table 2. 2: Inclusion and exclusion criteria for systematic review 40

Table 3. 1: Ethical consideration and protocol implemented to minimise the risks to the study 65

Table 4. 1: Summary of participants' characteristics 78

Table 4. 2: Summary of the characteristics of the participants' child with autism 79

Table 4. 3: Summary of participants' receipt of historic and current interventions 80

Table 4. 4: Dependent variable constructs 84

Table 4. 5: Eight steps taken to develop the bespoke self–report survey 86

Table 4. 6: Internal consistency of items measuring constructs 88

Table 4. 7: Threats to internal validity and a summary of actions taken to minimise them 93

Table 5. 1: Pre- and post-intervention scores of parents' self reported perceived knowledge of emotional well-being and strategies to promote it 101

Table 5. 2: Pre- and post-intervention scores of parents' self reported knowledge of potential challenges for their child with autism in adolescence and strategies to support them. 105

Table 5. 3: Pre- and post-intervention scores of parents' self reported confidence in promoting the emotional well-being of their child with autism. 109

Table 5. 4: Pre- and post-intervention scores of parents' self reported confidence in supporting their child with autism through the potential challenges in adolescence that may impact upon emotional well-being. 113

Table 6. 1: Agreement between the researcher and '*blind rater'* in the coding decisions of extracts of data……..123

Table 6. 2: Strategies used by the researcher to support the rigour of the study……126

LIST OF FIGURES

Figure 2. 1 Identified stage of a systematic review 36

Figure 2. 2 Summary of process for review syntheses for the identification of relevant studies meeting the inclusion criteria. 41

Figure 2. 3 A summary of the studies that met the inclusion criteria of a systematic review of research. 45

Figure 3. 1 Overview of the module aims and content of the Autism, Emotional Well-being and Adolescence Programme 69

Figure 4. 1: Overview of the sample recruitment for the experimental group and wait-list control group 75

Figure 7. 1: Thematic report of themes and sub-themes relating to participants' reflections of their experiences of attending the Autism, Emotional Well-being and Adolescence programme 130

Figure 7. 2: Thematic report of themes and sub-themes relating to participants' subsequent experiences as a result of attending the Autism, Emotional Well-being and Adolescence programme 138

Figure 8. 1: Visual representation of the process of change supported by the AEWA programme 162

LIST OF APPENDICIES

Appendix A: Ethical Approval Letter 206

Appendix B: Example of information sheet given to participants (experimental group) 207

Appendix C: Example of initial contact letter providing an overview of the research and an invitation to participate 209

Appendix D: Consent Form 211

Appendix E: Measure developed to evaluate the Autism Emotional Well-being and Autism Programme (T1). 212

Appendix F: Intervention Fidelity Checklist 216

Appendix G: Inter-rater Intervention Fidelity Agreement Calculation 219

Appendix H: Groups of items to address constructs with Cronbach Alpha scores 222

Appendix I: Questions asked when piloting the questionnaire developed for evaluating the Autism, Emotional Well-being and Adolescence programme. 225

Appendix J: Adapted personal data questions for survey template to evaluate the Autism Emotional Well-being and Adolescence Programme (T2). 227

Appendix K: Effect Size 228

Appendix L: Interview Protocol 229

Appendix M: Example of part of a coded transcript 232

Appendix N: Tables identifying initial codes generated from transcript and how they relate to the identified themes and sub-themes 233

Appendix O: Tables illustrating data for each themes and sub-themes 239

Appendix P: Inter-Rater Agreement Calculations of themes by research question 266

* It has not been possible to include copies of actual intervention materials due to intellectual property rights.

GLOSSARY OF ABBREVIATIONS

AEWA	Autism, Emotional Well-being and Adolescence
BPS	British Psychological Society
CCP	Calm Child Programme
CBT	Cognitive Behavioural Therapy
EET	Education, Employment and Training
EP	Educational Psychologist
EPT	Educational Psychology Team
HCPC	Health Care Professionals Council
NICE	National Institute Health and Care Excellence
RCT	Randomised Control Trial
TEP	Trainee Educational Psychologist
UK	United Kingdom

ABSTRACT

Introduction: Promoting the mental health of young people is identified as a key priority in the United Kingdom (Department of Health & Department for Education, 2017). Particular groups in the population are at an increased risk of poorer mental health outcomes, for example, it is known that there is a high comorbidity between autism and mental health conditions, with an increase in prevalence around adolescence (de Bruin, Ferdinand, Meester, de Nijs & Verheij, 2006). Consequently, there has been a call for research that explores approaches to support the management of emotional issues for people with autism (Pellicano, Dinsmore & Charman, 2014). In response, this study presents the first evaluation of the Autism, Emotional Well-being and Adolescence (AEWA) psychoeducation programme for families of children with autism. The programme aims to develop parents' understanding of emotional wellbeing and how to promote it, with a particular focus on adolescence.

Method: A mixed methods approach was used in the study. The quantitative aspect of the study utilised a quasi-experimental pre- and post-design to explore the relationship between the AEWA programme and parents' perceived knowledge and confidence. Data was collected from nine participants in the experimental group and ten participants in the wait-list control group using a specifically constructed measure. The qualitative design involved exploring patterns in the experiences of six participants who attended the AEWA programme, using thematic analysis on the data gathered in semi-structured interviews.

Results: The quantitative results suggested that attending the AEWA programme leads to an increase in parents' perceived knowledge and confidence in their ability to meet the emotional well-being needs of their child with autism, through the potential challenges of adolescence. These results were supported by the qualitative findings. The thematic analysis results suggest that participants valued the content of the programme, the structure and approach to delivery and the opportunity to come together offered by the

programme. It was also suggested that following the AEWA programme, participants experienced some changes and challenges.

Conclusion: The evidence suggests a psychoeducation programme aimed at parents of children with autism, focusing on emotional well-being and challenges in adolescence, can have a positive impact on parents. This has the potential to support the developmental context of individuals with autism, as they grow older and the challenges change. Given these finding and considering the methodological limitations identified in this study, it appears research would benefit from further investigation in this area.

CHAPTER 1 – INTRODUCTION

1.1 Context for the research

In the United Kingdom (UK), there is currently a discourse around the importance of improving the mental health of children and young people, with national government strategy seeking to identify different approaches to promoting emotional well-being (Department of Health & Department of Education, 2017). It is known that particular groups of children and young people are at an increased risk of poor mental health, for example, there is a high comorbidity with autism and mental health conditions (de Bruin et al., 2006). Consequently, there has been a call for research into the identification of approaches to support individuals with autism as they grow older and the challenges change, particularly with the management of emotional issues (Pellicano, Dinsmore & Charman, 2013).

In response to the recognised need to promote the emotional well-being of children and young people with autism, an Educational Psychology Team (EPT) developed the Autism, Emotional Well-being and Adolescence (AEWA) programme for parents of children with autism. The psychoeducation programme was developed using their knowledge of psychological theory and theoretically informed approaches to intervention.

1.2 Focus of the research thesis and its unique contribution

The purpose of this research is to undertake the first evaluation of the locally developed programme. Using a mixed method approach the study seeks to identify if the programme's impacts upon parents' knowledge and confidence in supporting the emotional well-being of their child with autism, specifically through the potential challenges of adolescence. The study also aims to explore patterns in parents' experiences both while attending the programme and also subsequently.

In addition, this study is to consider more broadly the use of psychoeducation programmes as an approach to meeting the needs of young people with autism as they approach adolescence.

1.3 The researcher's professional and personal interest in the research topic

The researcher first developed an interest in the emotional well-being of young people through her career supporting young people 13-19 years old to engage in education, employment or training (EET). During this time they developed an appreciation of the importance of young peoples' emotional well-being, due to the influence it has upon their ability to take up opportunities in EET and participate in their community.

This study was conceived while the researcher was on a two-year placement as a trainee educational psychologist (TEP) in the local authority (LA) where the AEWA programme was developed. Through her work as a TEP, the researcher was involved in a range of casework in which young people with autism were being affected by emotional needs. This highlighted for her the relevance of the AEWA programme that was being implemented by the EPT.

In a quest to ensure practice in the EPT was evidence-based, it was agreed the researcher would undertake the evaluative study to explore the impact of AEWA programme. The study undertaken is presented within this thesis.

1.3 Stakeholder Involvement

It is recognised that there are a number of stakeholders in the research presented. As part of ensuring the integrity of the research, each of the identified stakeholders were consulted and agreement for the research was gained.

This research is completed as part of a Doctorate in Applied Educational Psychology at the University of Nottingham, this being the professional training required to become an educational psychologist. The researcher is committed to undertaking rigorous research that makes a unique contribution to the evidence

base of their chosen profession. Ethical approval was gained for the research (Appendix A) and the guidelines for research provided by the institution were followed (University of Nottingham, 2013).

The LA employing the researcher was consulted about this research and agreement was gained from the strategic lead for the EPT. Agreement and support for the research was also gained from the senior educational psychologists responsible for developing and delivering the AEWA programme. It was viewed that the study would provide information about efficacy of the programme and the outcome would be used to inform decisions about the future commissioning of the AEWA programme and any required changes.

Parents of children with autism are also identified as stakeholders in this research; as potential beneficiaries of the intervention focused upon in this study. Throughout the design and implementation of this study those parents agreeing to be involved in the research were consulted with and consent gained for their participation.

1.4 Structure of the Research Thesis

This thesis is arranged into nine chapters. Following this introductory chapter, relevant literature is reviewed and research aims are identified. The study then progresses on to provide an overview of the methodological designs used before the results of the study are the identified and discussed in relation to relevant research. Methodological limitations in the design of the study are then considered and implications for practice, before a summary of the empirical findings of the study is provided to conclude the thesis.

CHAPTER 2 - REVIEW OF LITERATURE

2.1 Introduction to the chapter

The aim of this literature review is to explore theories and research in relation to the key topic area relevant to this study.

This review starts with focusing on autism, a neurodevelopmental condition. Literature around autism, the diagnosis, the prevalence and the potential impact of autism on children, young people and their families is explored.

The review of literature then goes on to consider possible challenges for young people with autism, with an emphasis on the developmental period of adolescence. Ways to support young people with autism during this time are discussed with a focus on relevant issues to adolescence such as sexuality and relationships, transition and developing independence.

Research suggests that there is a high comorbidity between autism and mental health conditions so approaches to support emotional well-being to reduce poor mental health outcomes, particularly for individuals with autism are then considered.

Research is then reviewed about the use of parent education programmes as an approach to intervention to achieve positive outcomes for parents and their children. A focus of the use of parent programmes with parents of children with autism is specifically explored.

The final part of the literature review seeks to identify research that looks at the use of parent education programmes as the sole approach to intervention to promote the emotional well-being of children and young people with autism.

2.2 Autism

2.2.1 Definitions of Autism Spectrum Disorder

Autism is a widely known and is recognised as a developmental condition. The current conceptualisation of autism was influenced by the pioneering work of Kanner (1943) and Asperger (1944) who viewed the impact of the condition on an individual's development as distinctively different from any other previously identified. Since their seminal work conceptualising autism, there has been extensive research into the condition. Wing and Gould (1979), proposed that autism became recognised as existing on a continuum and identified the presence of a 'triad of impairments', in social interaction, social imagination and social communication.

The umbrella term Autistic Spectrum Disorder (ASD) first introduced by Wing (1993) is used to encompass the range of different subgroups within the autistic condition to reflect a continuum, which Asperger Syndrome and Pervasive Development Disorder not otherwise specified (PDD-NOS) are included. ASD is also referred to as Pervasive Development Disorder (PDD) an overarching term, used to catagorise disorders characterised by delays in the development of socialisation and communication skills.

ASD is often considered to be a neurodevelopmental disorder. It is a heterogeneous condition with an extremely diverse presentation, with individuals with ASD having their own unique profile. Currently, in the United Kingdom, the *International Classification of Diseases 10* (ICD-10; World Health Organisation, 1996) is used to diagnose ASD, with the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013) also widely used internationally to classify the condition. The diagnostic guidance identifies ASD as the presentation of symptoms in early development, which are identified by persistent deficits in social communication and social interaction across contexts, along with restricted, repetitive patterns of behaviour, interests or activities.

Although widely used, it is acknowledged that the conceptualisation of ASD is

controversial. Despite extensive research there is no known aetiology for autism and no genetic or biological markers for the condition or neurological features of ASD (Muller & Amaral, 2017). It has been suggested that ASD as a term should be abandoned as it lacks neurobiological and construct validity (Waterhouse, London & Gillberg, 2016). Instead of a disorder to be catagorised, Baron-Cohen et al. (1997) argues that it should be viewed as extreme systemizing behaviour.

The researcher acknowledges that there is a debate around the conceptialisation of ASD, of which a full exploration is beyond the scope of this paper. As the needs associated with ASD are prevalent in society, ways to support individuals to promote better outcomes requires consideration, so for the purpose of this paper, the existence of ASD as a meaningful concept is accepted.

2.2.2 Terminology

It is recognised that individuals and groups have different preferences for a variety of terms, including autism spectrum disorder, autism spectrum condition and autism spectrum difference. Research has shown in the UK's autism community, that there is no consistent agreement on the use of terminology (Kenny et al., 2015). In line with the terminology used by the Department of Health (2010), the term 'autism' will be used in this study for clarity and consistency.

2.2.3 Diagnosis of autism

Diagnosis of autism is through behaviour descriptions and the term is used as a categorical descriptor of behavioural manifestations. Categorical descriptors are used for their clinical usefulness to help with treatment decisions to intervention to try and achieve improved outcomes.

The National Institute for Health and Care Excellence (NICE) provide clinical guidance for the diagnostic assessment for autism. They identify a multidisciplinary autism team should be established in each local area, which should be made up of core professionals which include a paediatrician and/or a

child and adolescent psychiatrist, a speech and language therapist and a clinical and/or educational psychologist (NICE, 2011). Where concerns are identified about a child or young person linked to possible autism, a referral is made for an Autism Diagnostic Assessment, which is completed often through standardised tests, the taking of developmental history and clinical interview (Matson, 2007).

2.2.4 Prevalence of autism

In the UK, the estimated prevalence of autism is varied; research by the Department of Health in Northern Ireland suggested the prevalence of autism to be 2.2% in all compulsory school age children and young people aged 4-15 years old (Waugh, 2017). A survey by the Office of National Statistics of the mental health of children and young people in Great Britain found it to be 0.9% (Green, McGinnity, Meltzer, Ford & Goodman, 2005). Baird et al. (2006), suggests that around 1% of the child population have some form of autism, based on their findings of an estimated minimum of 116 in 10,000 from a sample population of children aged 9-10 years in the South Thames region. As knowledge and understanding of autism increases in the general population, it has been suggested the prevalence rates will increase as it is better detected and diagnosed (McConachie & Diggle, 2007).

2.2.5 The impact of autism

Children with a diagnosis of autism have been found to vary in their trajectories of development (Lord, Bishop & Anderson, 2015), with different combinations of symptoms changing over a person's lifetime (Hughes, 2012). A review of research suggested that across the autism spectrum, there is a general overall improvement in symptoms of autism with increasing age (Levy & Perry 2011).

Steinhausen, Mohr Jensen & Lauritsen, (2016) explored the long-term outcomes for adolescents and adults with autism. Their review of research found heterogeneity in outcomes linked to social and individual functioning: around fifty percent of individuals with autism had good or fair long-term outcomes with the other fifty percent having poor or very poor outcomes. Although varied

outcomes have been found, it has been identified that people with autism have poorer outcomes in adult life compared to their peer group in areas such as employment, accommodation, social inclusion and mental health (Steinhausen, et al., 2016).

Autism can also have a significant impact on families. It has been found to have a negative impact on parental self-efficacy, parenting stress, parent physical and mental health, the parent-child relationship and the family system (Place, 2016; Karst & Van Hecke, 2012; Rao & Beidel, 2009).

The societal cost of autism has also been considered, with research looking at the financial cost to society from the costs of service delivery and loss of production. In the UK, it is estimated that the average lifetime cost for someone with autism and an intellectual disability to be 1.23 million pounds and approximately 0.80 million pounds for someone with autism without an intellectual disability (Knapp, Romeo & Beecham, 2009).

2.2.6 Autism and research in the UK

Autism is a widely used concept, which has been of great focus for research over the last few decades. In the UK, research into autism has primarily focused on the underlying cause, with very limited research into diagnosis and identifying evidence-based interventions to support individuals with autism and their families (Pellicano, Dinsmore & Charman, 2014).

Pellicano et al. (2014) undertook a large-scale study involving 1517 participants, to ascertain the views and priorities for autism research from the perspective of the UK autism community. Stakeholder groups included adults with autism, immediate family members of people with autism, practitioners working with people with autism and researchers. All stakeholders prioritised a need for applied research in the UK into evidence-based services and interventions and support for people with autism and their families. Research that focused on service and interventions that would make a difference to people with autism in their everyday lives, associated with the management of practical, social and emotional issues were identified as a high priority.

2.2.7 Summary

This section has provided a brief overview of autism considering terminology and definition. As identified, autism is characterised by deficits in social communication and social interaction across contexts, along with restricted, repetitive patterns of behaviour, interests or activities. Individuals with autism present with a unique profile of deficits making them a heterogeneous group, with varied developmental pathways.

Although there are variations in the estimates of the prevalence of autism, it is accepted there is a significant number of children and young people in the UK experiencing deficits associated with autism. Given that individuals with autism and their families have poorer outcomes than their typically developing peers, there is a clear rationale for research into how best to promote better outcomes for this population.

The following section will explore emotional well-being and mental health in children and young people, with a focus on those with autism. Related outcomes with positive emotional well-being and poor mental health will be discussed, along with interventions to support.

2.3 Emotional Well-being and Mental Health

2.3.1 Definition of Emotional Well-being

The Dual-Factor Model of Mental Health (Suldo & Shaffer, 2008) suggests that mental health is a complete status, which includes both positive and negative mental health states. Mental health is more than the absence of mental illness, but includes a strong sense of well-being reflecting facets such as life satisfaction and positive affect. Emotional well-being describes the positive status of an individual's mental health. The National Institute of Health and Social Care Excellence (NICE, 2013) defines emotional well-being as: being confident and happy, while not being anxious or depressed. Psychological well-being is defined as an individual's ability to be resilient, manage emotions, problem solve, be autonomous, express empathy and be attentive (NICE, 2013). The '*broaden and build theory*' (Fredrickson, 2000) suggests that positive emotions derived from psychological well-being can promote an upward spiral to emotional well-being (Fredrickson & Joiner, 2002). In much of the research, emotional and psychological well-being are not differentiated and used interchangeably, so for the purposes of this research the two constructs will be discussed under the term emotional well-being.

2.3.2 Emotional well-being and mental health in children and young people

A national survey indicated ten percent of children and young people (aged 5-16 years) have a clinically diagnosable mental health problem which includes: emotional disorders such as anxiety or depression; conduct disorder and hyperkinetic disorder (Green et al., 2005). In the UK, a majority of mental health illnesses have been found to start before adulthood, with around 50% starting before the age of fifteen and 75% by the age of twenty-four (Kessler et al., 2005). The average age of the onset of anxiety disorders, such as: social anxiety and generalised anxiety disorder, has been found to be eleven years (Mental Health Foundation, 2016).

Despite the prevalence of psychological difficulties, it has been identified that a low number of individuals who would benefit from intervention are accessing

appropriate support. Less than 25% – 35% of those individuals with a diagnosable mental health condition access support (Green et al., 2005). Furthermore, there are others who would potentially benefit from intervention to support who are experiencing psychological issues which are not clinically significant.

2.3.3 Importance of emotional well-being

Good mental health and positive emotional well-being are the foundation for people's positive social, physical and mental health outcomes. Poor emotional well-being can have a negative impact on the short and long-term outcomes for young people. It has been found that it can impact on the long and short-term social and economic outcomes for young people (Colman et al., 2009). Emotional well-being is also known to impact upon a child or young person's behaviour, cognitive abilities and learning, influencing direct and indirect educational outcomes (Public Health England, 2014; Morrison Gutman & Vorhous, 2012). Long-term, adults who as children and young people struggled with psychological problems, have been found to work fewer hours, earn less money and be more likely to be unemployed (Centre for Longitudinal Studies, 2015).

2.3.4 Approaches to promote emotional well-being

Considering the importance of good mental health for individual outcomes and the prevalence of problems experienced by children and young people, it is important to identify how to promote emotional well-being to reduce the risks of poor mental health.

The UK government has identified a commitment to improving mental health and well-being, recognising the impact it has on children and young people. In a national report by the Children and Young People's Mental Health Taskforce (2015), key approaches to supporting mental health were identified, these included: the promotion of good mental well-being and resilience; work to prevent mental health problems from arising; and early identification of need.

Building resilience is a recognised approach to promoting emotional well-being and protecting against poor mental health outcomes. Resilience can be conceptualised as the dynamic processes, which enables an individual to positively adapt despite adversity (Luthar, Cicchetti & Becker, 2000). Resiliency theory has come out of research into mental health that has explored the variance in individual outcomes when faced with adversity (Masten, 2007; Masten, Best, & Garmezy, 1990).

A range of risks or challenges to development have been found to inhibit resilience, increasing the probability of poorer outcomes for an individual, while conversely protective factors or functions have been identified that promote resilience and increases the probability of positive outcomes (Masten & Tellegen, 2012). Risk and protective factors interact in the process of resilience; with no one factor promoting resilience in isolation (Fergus & Zimmerman, 2005). Research has shown that protective factors can evoke other protective factors to promote resilience, having what is known as the 'cascade effect' (Luthar, Sawyer, & Brown, 2006).

A strong positive correlation has been found between resilience and well-being, with individuals reporting higher well-being, also reporting higher resilience. Conversely, those reporting lower well-being have been found to report lower resilience (Mguni, Bacon & Brown, 2012). Building resilience, therefore, has the potential to promote an individual's future well-being and protect against negative mental health outcomes. Risk and protective factors to promote resilience have been located at three levels: the individual, family and environment outside of the family (Coleman, 2007; Eriksson, Cater, Andershed & Andershed, 2010).

Protective factors have the potential to support an individual's resilience and promote emotional well-being. For example, home and school connectedness has been found to predict well-being (Shochet , Dadds, Ham & Montague, 2006; Jose et al 2012) and individuals with high self-esteem savour positive experiences which promotes well-being (Wood, Heimpel & Michela, 2003). Therefore, interventions that seek to minimise risk factors and promote

protective factors have the potential to support an individual's emotional well-being and positive mental health.

Emotional regulation has been identified as an important protective factor for resilience (Artuch-Garde et al., 2017). Emotional regulation has been described as the processes influencing experience and expression of emotions (Gross & John, 2003). Considering the cascade effect, emotional regulation also supports other protective factors such as academic success (Burić, Sorić & Penezić, 2016; Graziano, Reavis, Keane & Calkins, 2007) and social connectedness (Zhao & Zhao, 2015). It is therefore not surprising that poorer emotional regulation has been associated with poorer emotional well-being and poorer mental health outcomes (Berking & Wupperman, 2012; Hu et al., 2014).

There has been extensive research into the use of cognitive-behavioural approaches used to support emotional regulation and promote emotional well-being to reduce mental health problems such as anxiety (James, Soler & Weatherall, 2007). Cognitive behavioural approaches are underpinned by the principle that thoughts, feelings and behaviours are interlinked, with an individual's thoughts and feelings guiding their behaviour (Kendall, 1991). Part of cognitive-behaviour approaches involves making individuals explicitly aware of these links, so they can explore and make adaptations (Stallard, 2003). Cognitive behavioural approaches often involve psychoeducation to develop an individual's knowledge and skills to support their emotional regulation, cognitive reframing and problem solving (Velting, Setzer & Albano, 2004).

Interventions underpinned by cognitive-behavioural theory have been found to significantly reduce anxiety in both typically developing children and adolescents (Hofmann, Asnaani, Vonk, Sawyer & Fang, 2012; Cartwright-Hatton, Roberts, Chitsabesan, Fothergill & Harrington, 2004). Due to the strong evidence base for cognitive-behavioural approaches, they have been recognised by the World Health Organisation (WHO) for the prevention of mental disorders (WHO, 2004).

2.3.5 Emotional well-being in children and young people with autism

The Department for Education (2016) identified neurodevelopmental disorders such as autism as a risk factor to an individual's emotional well-being. Psychosocial needs associated with autism in daily life can have a negative impact on the emotional well-being of children and young people with autism. It has been found that a majority of children with autism have a comorbid psychiatric condition, with the most commonly occurring conditions being identified as anxiety, attention deficit hyperactivity disorder (ADHD) and mood disorder (Hepburn, Stern, Blakeley-Smith, Kimel & Reaven, 2014; de Bruin et al., 2006). In a national survey, almost ninety percent of parents with children with autism had sought help for their child's mental health problems (Green et al., 2005).

In adolescent young people with autism, anxiety disorder or symptoms of anxiety are the most commonly co-occurring condition (Vasa et al., 2014), with it being suggested up to 40% of adolescents with autism experience clinically elevated rates of anxiety or an anxiety disorder (van Steensel, Bögels, & Perrin, 2011).

Poor emotional well-being can have a negative impact on the daily functioning of a children and young people with autism, for example, in their ability to participate in school, home and the community (Davis, White & Ollendick, 2014). Not only do these poor outcomes have a negative consequence for the individual's experiences but psychiatric conditions such as anxiety disorder in people with autism also has a high societal cost (van Steensel, Dirksen & Bögels, 2013).

There are challenges in the psychiatric diagnostic process for individuals with autism, which has implications for early intervention. Assessments involving self-report impact on diagnosis as children and young people with autism often have difficulties identifying and reporting their own anxiety symptoms (Mazefsky, Kao & Oswald, 2011). Symptoms of underlying psychiatric conditions such as anxiety may be assumed to be part of the autism diagnosis (Wood & Gadow, 2010), due to overlap in the associated features contributing

to diagnostic overshadowing. Psychosocial masking also impacts upon diagnosis of mental health conditions, as symptoms may be overshadowed by the manifestation of behaviours from the difficulties associated with autism.

2.3.6 Why are young people with autism experience poorer mental health outcomes

As highlighted in section 2.2.1 autism is characterised by needs in areas such as social communication and social interaction across contexts, along with restricted, repetitive patterns of behaviour, interests or activities (ICD-10; World Health Organisation, 1996). These core needs have been associated with increased stressful experiences for individuals with autism and have been found to promote anxiety (Wood & Gadow, 2010).

Social needs have been associated with increased stress and anxiety in young people with autism. It has been identified through research that: social loneliness relates to anxiety (White & Roberson, 2009; Bellini, 2006); quality of social relationships have a negative relationship with anxiety (Eussen et al., 2012); and social functioning impairments relate to increased social anxiety (Chang, Quan & Wood, 2012). Awareness of social differences has also been demonstrated to contribute to increased stress, contributing to anxiety (Belinin, 2004).

Other needs associated with autism have also been found to impact on the well-being of individuals with autism. Intolerance of uncertainty associated with rigidity in thought within young people with autism is related to increased anxiety (Neil, Olsson, & Pellicano, 2016; Boulter, Freeston, South & Rodgers, 2013). Individuals with autism can often experience aversions to sensory stimuli, with sensory over-responsivity associated with increased anxiety in individuals with autism, although the causal mechanisms have not been established (Green & Ben-Sasson, 2010).

2.3.7 Approaches to promote emotional well-being in children and young people with autism

Given the prevalence of potentially poor mental health outcomes for children and adolescents with autism, there is a need to raise awareness on how autism can impact on mental health to support early and preventative psychosocial intervention.

Interventions used to promote emotional well-being in the typically developing population have been found to be effective with children and young people with autism. In some instances, interventions have been adapted to meet the needs of the population (Wood et al., 2009), in others there has been no change to the content (Conaughton, Donovan & March, 2017).

Shochet et al. (2016) suggests that given the significant adversity the neurodevelopmental disorder can present there is a need to develop protective factors to promote the resilience process of children and young people with autism. Interventions that target the development of resiliency in young people with autism have been found to promote their self-efficacy, self-confidence, social skills and affect regulation (Mackay, Shochet & Orr, 2017). Promoting these areas are important as it has been found children and young people with autism rate their self-esteem significantly lower than their typically developing peers. Additionaly, low self-esteem has been found to negatively correlate with poorer mental health outcomes in typically developing young people and young people with autism (Moher et al., 2017; Cooper, Smith & Russell, 2017). Consequently, interventions that seek to promote resilience have the potential to promote emotional well-being of children and young people with autism.

Emotional regulation has been identified as a protective factor to promote resilience and positive emotional wellbeing. Systematic reviews of research, have found psychosocial interventions to support emotional regulation, based on cognitive behavioural approaches to be effective in promoting wellbeing through reducing anxiety in children and adolescents with autism (Kreslins,

Robertson & Melville, 2015; Ung, Selles, Small & Storch, 2014). Interventions underpinned by cognitive-behavioural approaches, delivered outside the clinical setting have been found to be effective in reducing negative mental health outcomes such as anxiety, in young people with autism. For example when delivered in the context of the family (Reaven, Blakeley-Smith, Culhane-Shelburne & Hepburn, 2011) and in schools (Clarke, Hill & Charman, 2016; Luxford, Hadwin & Kovshoff, 2016; Slack, 2013), using manualised approaches to intervention such as Exploring Feelings: Cognitive Behavioural Therapy to Manage Anxiety for children aged 10-12 (Atwood, 2004) and the FRIENDS for Life Program (Barrett, 2010).

In a systematic review of research, the use of parent programmes as an approach to intervention have been found to be effective for promoting the social and emotional development of children (Barlow et al., 2010). However, as will be discussed later in the review, there has been little research into the efficacy of parent programmes to promote the emotional well-being of children and young people with autism.

2.3.8 Summary

To conclude, positive mental health can be supported through promoting emotional well-being. Given the prevalence of mental health problems in children and young people particularly those with autism, it is important to identify needs early and implement effective interventions that promote emotional well-being. This is particularly important given the potential negative short-term and long-term outcomes for children and young people who experience poor mental health.

The development of protective factors such as self-esteem and emotional regulation to promote resilience have been identified as a way in which the emotional well-being of both typically developing children and young people and those with autism can be supported.

Adolescence has been recognised as a time needing special attention due to the physiological, neurodevelopmental, psychological and emotional changes

individual's experience (World Health Organistation, 2004). Due to the changes in adolescence, it has been found to be a time where there is an increase in the prevalence of poor mental health outcomes, particularly those with autism (de Bruin et al., 2006). The following section will focus on adolescence, considering the potential challenges individuals face, particularly those with autism, which can impact on emotional well-being. Approaches to support during this development stage will also be discussed.

2.4 Adolescence

2.4.1 Definition of adolescence

Adolescence is the period between puberty and adulthood. It represents the transitional stage an individual passes through between childhood and becoming an adult. The World Health Organisation (2004) recognise adolescence as being between the ages of ten and nineteen years old. It is described as a time when individuals develop the knowledge, skills and attributes required for adulthood (Lloyd, 2005).

2.4.2 Adolescence and autism

For individuals with autism, adolescence can potentially be a challenging time. During this period, there is often an increase in self-awareness and young people with autism can develop an increased awareness of differences between them and their typically developing peers. Complex social expectations in adolescence can also be challenging for individuals with autism to navigate because of the deficits they exhibit in social understanding.

The changes that occur during adolescence have been found to impact on emotional well-being. De Bruin et al. (2006) found an increase in the occurrence of psychiatric conditions in adolescents with autism, reporting rates of anxiety increased from around 14% in childhood up to 37% during this period. Whilst it has been recognised that adolescence is a challenging time especially for those young people with autism, there is a lack of literature into the methods to support these individuals (Matson, Mahan and Matson, 2009).

2.4.3 Positive approaches to support adolescents with autism

Psychoeducation is an important approach for parents of adolescents with autism. It has been identified that the delivery of psychoeducation to parents of children with autism can help develop parents' understanding of how best to support the development of their child's social skills and promote independence through small steps during adolescence (Reaven, 2010). Consequently,

interventions involving psychoeducation have the potential to help parents to support their child to manage possible challenges faced in adolescence.

2.4.4 Autism, sexuality and relationships

Sexuality is a part of life and is developmentally as appropriate for individuals with autism as anyone else (Hellemans, 2007). This understanding is relatively new (Kellaher, 2015), contrasting previous suggestions that individuals with autism were asexual or that sexuality is a particularly problematic issue for them.

Individuals with autism may display a variety of sexual behaviours, typical sexual needs and wish to engage in intimate relationships (Gougeon, 2010). Recent studies indicated that a large majority of high-functioning adults with autism are interested in romantic relationships (Strunz et al., 2017), with over half of adults with autism sampled in a large study found to be in relationships and living with their partner (Dewinter, De Graaf & Begeer, 2017).

There is increased risk that individuals with autism will present with sexually inappropriate behaviour, have poorer knowledge about privacy and have lower levels of sex education due to needs associated with social understanding and functioning (Stokes & Kaur, 2005). In light of this, parents of children with autism hold increased concerns around their child's sexual development compared to parents of typically developing peers. Parents are reported to be concerned their child will demonstrate behaviours that may be misconstrued as provocative or sexually inviting and they fear their child will be sexually abused (Stokes & Kaur, 2005).

Sex and relationship education for children and young people with autism is of high importance to reduce the risks linked to sexual abuse, inappropriate sexual contact with others, and sexual behaviour in public places (Travers & Schaefer Whitby, 2015). Social, communicative and behavioural difficulties associated with autism, mean adolescents with autism require targeted education around sexuality development, adapted to their capacities, to ensure it is effective and appropriate, promoting healthy sexuality development (Hellemans, Colson,

Verbraeken, Vermeiren & Deboutte, 2007). The use of social stories, social behaviour mapping based on cognitive behavioural strategies and applied behavioral analysis are all approaches that have been identified as useful for supporting the development of social skill components in sex and relationship education (Ballan & Freyer, 2017).

The primary source of sex and relationship education for adolescents with autism was found to be parents, with individuals less likely to gain information from either peers or the media compared to their typically developing peers (Stokes, Newton, and Kaur, 2007). Parents want to support the healthy sexual development of their children but require support to do so (Ballan, 2011). They need support to understand what their child with autism needs to be taught about sex and relationships to help promote healthy development, support emotional well-being and prevent exploitation and problem behaviours.

2.4.5 Transition in adolescence for individuals with autism

The most common transition made during adolescence in the UK is that between primary and secondary school. Individuals are required to navigate simultaneous changes that occur in their school environments, social interactions and the academic expectations upon them (Anderson, Jacobs, Schramm & Splittgerber, 2000). This time requires both psychological and emotional adjustment, which can be difficult for some young people.

Experiences during transition have been found to impact upon well-being and attainment. In a large-scale study involving two thousand young people in Scotland, West, Sweeting & Young (2010) found that poorer school transitions at the age of 11 years old predicted lower social and emotional outcomes and lower academic attainment.

Consequently, the transition between primary and secondary school times requires careful planning and attention, particularly for those children and young people with Special Educational Needs as highlighted in the Special Educational Needs and Disability (SEND) Code of Practice (Department for Education and Department for Health and Social Care, 2015).

The Autism Education Trust has identified times of transition as being particularly difficult for individuals with autism (Stobart, 2012) but it is important to note that as children and young people with autism are a heterogeneous group, experiences will be varied.

Neal & Frederickson (2016) found some young people with autism experienced anxiety prior to transition, with feelings linked to uncertainty and in many cases others reported experiencing excitement. Following transition, the young people expressed positive views of their new schools and described the transition as a time of change, as they experienced differences in the environment, curriculum and school systems.

Mandy et al. (2015) identified there were no marked increases in difficulties across transition for individuals with autism. By contrast, Hannah and Topping (2012) found transition experiences to be variable for young people with autism, with some young people experiencing increased anxiety, while others did not. The variation in experiences was accounted for by individual differences identified prior to transition.

Facilitators to a successful transition for young people with autism have been found to include practical information and advice, positive approaches such as school visits, discussions about transition and individualised approaches to meet the pupil's needs (Neal & Frederickson, 2016).

2.4.6 Promoting independence in young people with autism

The independence of young people with autism can often be affected by the core needs associated with the condition. Social and cognitive needs can inhibit independence by affecting an individual's ability to initiate behaviour and generalise their skills, whether it be social or practical (Taylor & Seltzer, 2010). Intervention strategies that create an over-reliance on the guidance from others, has also been suggested as inhibiting the development of independence in individuals with autism, creating a prompt dependence (Taylor & Seltzer, 2010).

The consequences of reduced independence for young people with autism include low rates of employment, housing and social engagement in their communities (Taylor & Seltzer, 2010; Howlin, Goode, Hutton & Rutter, 2004). Unmet independence needs for young people with autism including social contact, appropriate daytime activities and safety of self have been shown to have significant associations with the level of caregiver burden experienced (Cadman et al., 2012).

Promoting independence in individuals with autism has been identified as a key priority for research (Pellicano, Dinsmore & Charman, 2014). In the study, parents highlighted a need for research into developing an understanding of how to help promote independence and support their children to lead '*safe* lives.' In addition, autistic adults and parents of children and young people with autism raised the importance of getting people with autism into employment and keeping them there.

Increasing independence for young people with autism can be facilitated by encouraging parents to consider ways in which they can support their child to take small steps, while also being considered as part of interventions to support (Reaven, 2011). In a review of interventions to promote independence of young people with autism, work systems that seek to reduce the reliance on the prompts of others (Hume, Loftin & Lantz, 2009). However, overall it has been found that there is very little evidence available on approaches to support young people with autism transition to adulthood, considering employment, social and adaptive outcomes (Taylor et al., 2012).

2.4.7 Summary

Adolescence is a time of change where young people with autism face new life challenges, which can potentially impact on their emotional well-being and therefore requires relevant and tailored support.

As highlighted, in adolescence there is a clear role for parents in supporting their child with autism, focusing on needs relevant to the stage of development which may include: promoting emotional well-being: preparation for

transitions; education around sex and relationships to promote the development of healthy relationships; supporting the development of their child's independence.

Despite the potential challenges identified in adolescence for young people with autism, there is limited research into ways to support during this period. It has been widely acknowledged that parent education programmes are a way in which parents can be supported to develop the knowledge and skills required to support their child with autism. The use of parent education programmes will be explored in the following section.

2.5 Parent Education Programmes

2.5.1 Definition of Parent Education

Parent education broadly describes the process of giving parents or other primary care givers knowledge and skills to support their child's development (Schultz, Schmidt, & Stichter, 2011). They are focused on improving parent practices through the use of systematic activities often delivered by a professional. Through this approach to intervention parents can mediate intervention to support improved outcomes for the child and their families (Cartwright-Hatton et al., 2011).

2.5.2 Parent programmes as an approach to intervention

Parent programmes are a well-established approach to intervention that focusing on changing parent's behaviour to support change in their children's behaviour (Forehand, Jones & Parent, 2013). Parent education programmes or parent training are broadly designed to provide parents with information to develop their knowledge and skills with the purpose of facilitating positive change for their child.

There is a great variation in the structure of parent programmes targeted at parents of children of differing ages, with differing needs. The content of parent education programmes can vary greatly, drawing upon a range of psychological theories. Traditionally they have predominantly been underpinned by behavioural approaches, but programmes are now drawing upon Family Systems approaches, Psychodynamic approaches and Cognitive Behavioural approaches(Forehand et al., 2013).

The role parents take in intervention delivery can differ depending on the target outcome (Forehand et al., 2013). Parents' roles may include: a consultant, providing information about the child; a collaborator, acting as a therapist to support the child's acquisition of coping skills; co-clients, when they are able to utilise the skills developed through intervention for themselves, for example, they may learn to manage their own difficulties (Kendall et al., 2010).

Parent education programmes are currently recognised in the National Institute Health and Care Excellence (NICE) clinical guidelines as a treatment and indicative prevention response to recognised conditions such as ADHD (NICE, 2016) and oppositional defiant disorder or conduct disorder (NICE, 2013).

2.5.3 Rationale for parent programmes

Rigorous research into the efficacy of parent education programmes has found the approach to be effective in improving behaviour problems in children, suggesting a more user-friendly and cost effective method than clinic based interventions (Barlow & Stewart-Brown, 2000; Dretzke et al., 2005). Systematic reviews of research have demonstrated that parenting programmes have been found to be an effective approach: for promoting the social and emotional development of children (Barlow et al., 2010); improving parenting (Bennett, Barlow, Huband, Smailagic & Roloff, 2013); supporting the mental health of parents (Barlow, Smailagic, Huband, Roloff & Bennett, 2012); and increasing knowledge and skills to promote positive mental health outcomes (Forehand et al., 2013). Consequently, parent programmes have been identified as a way of increasing access to psychological therapies (McConachie et al., 2013).

Delivery of group parenting programmes has been identified as a cost effective approach to delivering interventions compared with interventions provided on a one-to-one basis (NICE, 2006). Due to the small investments required in the delivery of group based parenting interventions, maintained changes only need to be small to be an efficient use of resources (Department for Children, Schools and Families, 2007).

2.5.4 Ecological Systems Theory

Bronfenbrenner's Ecological Systems Theory (1977, 1979), takes a systems perspective to understand the developmental context of children, recognising proximal and distal factors impact upon a child's development. The hierarchical embedded systems influencing development include: the microsystem (a child's immediate environment); the mesosystem (the interactive connections between the microsystems); the exosystem (the indirect environment such as the

community); the macrosystem (the social-cultural environment); and the chronosystem (the influence of change over time on the systems impacting upon the child). Ecological systems theory suggested that the proximal systems closest to the child have the biggest influence on their development. Therefore, the family is recognised as having a significant influence upon a child's development. Parent education programmes focus on change in the 'micro system' to positivity influence an individual's development.

The importance of taking an ecological view and supporting the developmental context of children is emphasised in the current special educational needs and disability code of practice (Department of Education and Department for Health, 2014). The guidance promotes the role of parents in supporting the development of their child, highlighting a need to empower them with information and support, to strengthen their ability to meet the needs of their child.

2.5.5 Social Learning

Bandura's (1969) work on social learning theory highlights the significant role parents have in shaping their child's behaviour with children's learning being supported through the mechanism of modelling (Bandura, 1977). Vtygotsky's (1978) theoretical framework for learning also provides a supporting rationale for parent education, referred to as the 'Zone of Proximal Development' and considers the difference between an individual's actual level of development in problem solving and the level they can achieve through the support of capable peers or adults. Through parent education, parents can develop the appropriate knowledge and skills to provide appropriate *'modelling'* and *'scaffolding'* to support their child's learning, aiding the developmental process.

2.5.6 Parent programmes to promote children and young people's well-being

A review of research into the efficacy of developing parents' skills and knowledge in cognitive behavioural strategies, to reduce negative mental health outcomes such as childhood anxiety, concluded the involvement of parents as

intervention agents is an efficacious approach for children's anxiety relative to control conditions (Forehand et al., 2013).

There is a body of research into the efficacy of interventions that have involved parents in reducing their child's anxiety, primarily through the use of cognitive behavioural approaches (Cartwright-Hatton et al., 2011). It has been suggested that involvement of parents in interventions to reduce anxiety in children and young people has been found to more effective than cognitive-behavioural approaches that focus on the on the child alone (Brendel & Maynard, 2013).

Cartwright-Hatton et al. (2011) found evidence to suggest cognitive-behaviourally based parent intervention were an efficacious approach to reducing children's anxiety, with treatment gains found to have been maintained 12 months on. It therefore follows that when parents are given training in cognitive-behavioural approaches, they can become effective therapists in providing treatment for anxiety to their children, promoting their emotional well-being.

Research comparing the effectiveness of different delivery approaches of cognitive-behavioural interventions involving parents as lay-therapists, providing treatment for anxiety disorders in young children has been undertaken. Waters, Ford, Wharton, & Cobham (2009) found intervention delivery to just parents to be as effective in reducing anxiety as intervention delivery involving both the parent and child. In contrast, Monga, Rosenbloom, Tanha, Owens and Young (2015) suggested that when using cognitive behavioural therapy (CBT) programmes it is more efficacious to work with both parents and children than parents alone, having found significantly greater improvements in the child-parent group compared to the parent only group.

While there are inconsistencies as to which is the most efficacious approach to delivery, all studies have consistently identified that interventions based on cognitive-behavioural approaches delivered through parents did facilitate significant improvements in anxiety disorder symptoms after the intervention which were sustained (Monga et al., 2015; Waters et al., 2009; Cartwright-Hatton et al., 2011).

2.5.7 Parent programmes and autism

Parent involvement in interventions for children and young people with autism is highly desirable (Brookman-Frazee, Vismara, Drahota, Stahmer, & Openden, 2009). The National Initiative for Autism: Screening and Assessment propose that children with autism can be supported more efficiently and effectively by promoting change in the child's developmental context, highlighting the importance of educating and empowering parents (Le Couteur & Baird, 2003).

Early research shows the involvement of parents in intervention delivery for children with autism has been recognised as an approach for almost four decades (Schopler & Reichler, 1971). Systematic reviews of research have identified a range of parent education programmes being used to provide parents of children with autism with information about different approaches to intervention to achieve a range of outcomes for both the child and the parents (Patterson, Smith & Mirenda, 2011; Schultz et al., 2011; McConachie, & Diggle, 2007).

Schultz et al. (2011) reviewed thirty evaluation studies of parent education programmes, aimed at parents of children with autism. The parent programmes predominantly were aimed at children five years old or younger, focusing on social and communication skills development or improving behaviour. Skill increase was a frequently reported category outcome in the studies reviewed with parents increasing their skills in 87% of the studies reviewed and children improving targeted skills in 83% of the studies. The outcomes found by Schultz et al. (2011) were similar to the outcomes reported in other reviews of research (McConachie & Diggle; 2007; Patterson et al., 2011).

Parent programmes have been found to promote parental well-being for parents of children and young people with autism which is important considering the increased challenges and demands that parenting a child with autism can have on psychological stress (Hayes & Watson, 2012). First, developing parents' knowledge linked to autism has been found beneficial in reducing parental anxiety, stress and distress (Farmer & Rupet, 2013; Tonge et al., 2006; Izadi- Mazidi, Riahi & Khajeddin, 2015). Second, parent programmes

have been found to empower and raise the general level of parents' confidence for parents of children with autism (Tellegen & Sanders, 2014; Cutress & Muncer, 2014; Farmer & Rupet, 2013; McConachie & Diggle; 2007; Dillenburger, Keenan, Gallagher & McElhinney, 2004; Engwall & MacPhearson, 2003) and improve parents self-efficacy (Sofronoff & Farbotko, 2002) an important mediator in the relationship between parenting stress and increased depression/anxiety for parents of children with autism (Rezendes & Scarpa, 2011). Third, the positive impact of parent-to-parent support in the context of group parent training has been identified as promoting well-being (Patterson et al., 2011, McConachie, & Diggle, 2007).

2.5.8 Elements supporting parent programmes to be effective

The provision of parent programmes alone does not guarantee positive outcomes.) Issues of recruitment, retention and engagement need to be considered to support the effectiveness of parent programmes. It is known that interest and relevance are primary reasons parents may have for joining a programme and once attending the content, its perceived usefulness and the delivery and organisation of the programme supports retention (National Academies of Science, Engineering and Medicine, 2016).

A study exploring reviews of research into the effectiveness of parent programmes undertaken by the National Academies of Science, Engineering and Medicine (2016) identified a number of elements of a parent programmes that have been found to be effective to support families facing adversities. These included: viewing parents as partners; tailoring interventions to meet the specific needs of participants and creating opportunities for participants to receive support from peers attending.

The content of parent programmes is a key element affecting the effectiveness of the approach to intervention. Moran et al. (2004) concluded following a review of the literature that effective parent programmes are supported by: content that has clear objectives; is underpinned by the provision of factual information; develops knowledge of child development; and is theoretically informed drawing on approaches such as cognitive and behavioural methods.

Another key element central associated with effective parent programmes is the delivery. For example effective parent programmes have been found to be delivered by appropriately trained staff; be manualised to ensure the programme content is carefully structured and there is fidelity to the intervention in delivery; and provide opportunities for both group work and individual work (Moran, et al., 2004.).

The format of the delivery of effective parent education for parents of children with autism is varied. Interventions have been delivered in groups, one to one and in a combination of these approaches (Schultz et al., 2011). Research is also exploring how parent education can be delivered through the use of technology (Hepburn, Blakeley-Smith, Wolff & Reaven, 2016). The intensity, frequency and duration of the delivery of interventions with parents found to be efficacious also varies greatly. Some programmes involve a small number of short sessions (Tellegen, & Sanders, 2014), whereas others have been described as lasting a number of years (Oosterling et al., 2010) and as previously discussed some parent education involves the presence of the child while others do not.

Schultz et al. (2011) sought to identify the approaches to teaching used in education programmes for parents of children with autism but raised concern that a majority of studies did not explicitly identify how they had taught parents new skills and knowledge and has called for further research into what mechanisms support parent interventions to be effective.

2.5.9 Change processes in parent programmes

The aim of parent programmes is to promote change to benefit the developmental context of the child (Forehand, Jones & Parent, 2013). The focus of the change is dependent on the outcomes targeted by the programme. As highlighted in section 2.5, parent programmes may target affective or behavioural outcomes for either themselves as parents or for their children. Parent programmes can potentially achieve change through different mechanisms.

Theoretical insights from self-efficacy theory (Bandura, 1977, 2004) have been widely associated with change in research. It has been found that parents' self-efficacy is important as it indirectly affects parent behaviours (Jones & Prinz, 2005). Self-efficacy theory, therefore, is a useful framework to be drawn upon to consider how change can be facilitated through parent programmes.

Self-efficacy is a term used to describe an individual's belief that they will be successful in a specific situation or accomplishment of a specific task, involving an individual's self-appraisal of their capabilities. Bandura (1994) identifies four main sources of influence on self-efficacy, which include: individual performance accomplishments or mastery experiences; their vicarious experiences; the verbal or social persuasion they experience; and their physiological and emotional state.

The cognitive perceptions of control based on an individual's internal factor associated with their self-efficacy effects behaviour (Bandura, 1977, 2004). When individuals believe they are able to accomplish something they are more likely to engage in it, so people with high self-efficacy will view themselves as having control over the outcome, show commitment to achieving it and so will increase their efforts when faced with impending failure (Bandura, 1977, 2004).

Parent programmes have the potential to facilitate change by increasing parent's self-efficacy in meeting the needs of their children. Promoting the self-efficacy of parents will likely increase the role they feel they have in promoting their child's emotional well-being and supporting them through adolescence, even at challenging times. Mechanisms such as increasing an individual's knowledge and confidence can influence how parents self-appraise their capabilities of achieving a task, which has potential affective and behavioural consequences.

Self-efficacy is thought to influence how a task is perceived and can therefore influence the stress experienced by an individual (Bandura, 2004). It is known that people with high self-efficacy will view what they perceive as a difficult task more positively and as a challenge to be accomplished. Therefore, promoting

self-efficacy can also potentially have a positive impact on the emotional well-being of parents.

2.5.9.1 Promoting knowledge to facilitate change

Knowledge depends upon the acquisition of information, facts and skills through experience or education. The acquisition of knowledge is one way change can be facilitated. Many interventions to support parents have focused on developing parents' knowledge of child development, as it is a key mechanism to promote behaviour change: it is known that knowledge can guide parent attitudes and behaviours (National Academies of Science, Engineering and Medicine, 2016). It is nevertheless acknowledged that there is limited research directly relating to parent knowledge and child outcomes (Winter, Morawaska & Sanders, 2012).

The provision of information about child development is anticipated to support parents' understanding of what is happening for their child. By developing parent's knowledge of strategies, parent programmes aim to better equip parents to tailor their own behaviours and response to support the child and promote their emotional development.

In an exploration of reviews of what supports parent programmes to be effective Whitacker and Cowley (2010) highlight the importance of the content and delivery of parent programmes, to support the acquisition of knowledge. They suggest to support recruitment, retention and engagement of parents, the content of parent programmes need to be of relevance and interest to participants and theoretically informed. They also focus on the delivery of the content, highlighting the need for the content to be delivered by facilitators experienced in managing group process so it remains relevant to each parent.

2.5.9.2 Promoting confidence to facilitate change

Self-efficacy theory (Bandura 1986, 1992) highlights that more than the provision of knowledge is required to support change, suggesting an individual's attitude mediates whether knowledge will be used to transform behaviour.

Confidence relates to an individual appraisal on ones abilities or qualities. Promoting parents' confidence through parent programmes is recognised as a key factor in supporting their self-efficacy to potentially facilitate change. This is reflected in Whitacker and Cowley's (2010) conclusions that effective parent programmes embed the promotion of self-efficacy, through their content and the delivery.

Confidence can be influenced by social processes, with positive social experiences associated with its development. Social experiences on a parent programme are influenced by the delivery of the programme. Through the use of group facilitation skills, participants can receive support from their peers on the programme contributing to a collective experience and reducing feelings of isolation (Whittaker & Cowley, 2010). This is important as previous research has suggested that opportunity for social connectedness has been found to be associated with confidence (Jose, Ryan & Pryor, 2012) and through access to peers in a group intervention, individuals can receive validation (Catalano, Holloway and Mpofu, 2018).

To support participants to positively appraise their skills and qualities, promoting their confidence, recognising and valuing what they bring to the programme is important. Effective parent programmes can do this by viewing parents as partners, where the parents attending are viewed as equal to the practitioners delivering the programmes (National Academies of Science, Engineering and Medicine, 2016). Parent programmes where parents feel valued in their participation in activities and empathetic interaction styles, have been found to enhance the quality of interactions, build trust and support participation in programmes, support programme effectiveness (Jago et al., 2013).

2.5.10 Summary

In summary, parent education programmes have been identified as an efficacious approach to intervention to support a broad range of outcomes for parents and children. Parent programmes seek to create change in parents, often in their understanding, knowledge and skills to guide their behaviour to

support the developmental context of their child. Parent education has been used to support parents with children with autism, to meet a range of needs linked to developing parents understanding of autism, behaviour, social skills, communication needs and mental health. The format of the delivery of parent programmes has shown to be varied and although some factors to support parent education have been identified to be effective, there is a call for further research into what contributes to the effectiveness of parent education for parents of children with autism.

The understanding of parent education is built upon in the next section, which moves to an exploration of literature on how the use of parent education programmes as a stand-alone approach to intervention can be used to promote the emotional well-being of children with autism.

2.6 Review of Research

2.6.1 Introduction to the systematic synthesis of research

A systematic synthesis is a formal process of collectively reviewing different types of evidence, so a clear understanding of what is known from research can be established and how it is known (Gough, 2007). Systematically reviewing the research in this way will identify current literature relevant to the research, with the aim of developing a clear understanding of how parent programmes can be used to support the emotional well-being of children with autism.

Gough (2007) provides a map of the stages in a systematic review shown in Figure 2.1.

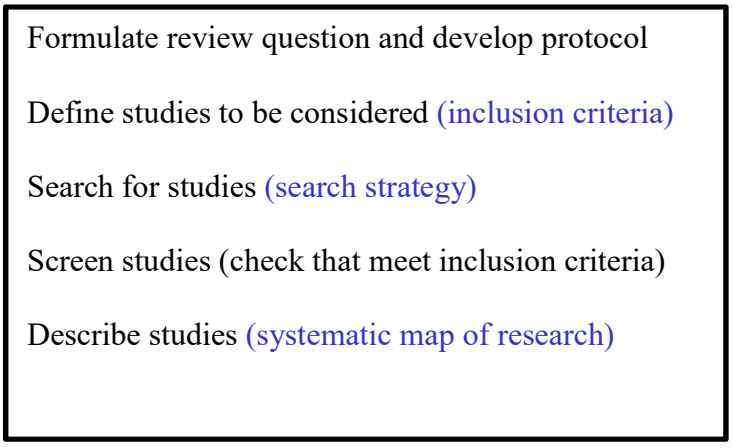

Figure 2. 1 *Identified stage of a systematic review (Gough, 2007, p.5)*

2.6.2 Review Question

This systematic review of research seeks to critically appraise existing research where parent programmes have been used to support the emotional well-being of children and young people with autism to consider the following review question:

- What research has been done to explore the effectiveness of parent programmes as an approach to intervention to support the emotional well-being of children and young people with autism?

- What does existing research tell us about the effectiveness of parent programmes as an approach to intervention to support the emotional well-being of children and young people with autism?

2.6.3 Protocol

An initial search of PsycINFO (OVID), Educational Research Information Center (ERIC) and Medline databases of literature was undertaken. PsycINFO was chosen as it specialised in behaviour and social sciences literature and research, making it relevant for finding scholarly research in psychology and ERIC were used to search education research. Medical research was also explored using Medline, a database for medical research that includes psychiatric research. It was deemed appropriate to search a medical database as medical guidelines such as NICE (2014) highlight the need to work with parents to support children and young people diagnosed with autism. A broad hand search of the scholarly literature was undertaken using Google Scholar, in an attempt to ensure relevant papers not on the databases searched were not missed. A secondary search was then completed by the researcher, reviewing the reference list of papers.

The search terms used to search each database to identify relevant literature on the 8th and 9th June 2017 are shown in Table 2.1

Concept	Search terms
Autism	Autis* ***OR*** ASD ***OR*** Asperger* ***OR*** Pervasive Development*
	AND
Parent education	Parent* education ***OR*** Parent* training ***OR*** Parent* Psychoeducation ***OR*** Parent* intervention ***OR*** Parent* program*
	AND
Emotional well-being	Emotional Well* ***OR*** Anxiety ***OR*** Resilienc* ***OR*** Self esteem

Table 2. 1: The search formula for the systematic search or research

The terms were searched in the title and abstract in all databases. The Keyword Identifier was also searched in the ERIC database, the Key Concept Descriptor in PsycINFO database and Identifier (keywords) in the Medline database. The search results from the identified databases were combined and the duplicate results were removed.

2.6.4 Screening the papers

The recommended methodology for screening papers, identified in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Liberati, Tetzlaff & Altman, 2009) was used to identify items for review. During the initial stage of screening papers, the titles were reviewed. Fifty-eight were removed as they were identified as duplicates and an additional two-hundred and seventy nine were discounted, as from the title it was clear they did not involve an intervention or it was an intervention not involving parents. The remaining forty-nine papers were fully screened against the criteria outlined in Table 2.2.

	Inclusion Criteria	Exclusion Criteria
Date of publication	2000 – Present	<2000
Literature format	Peer reviewed journals. PhD / Doctoral thesis	Books Reports Conference papers Instructional guidance on intervention
Sample	Parents of children and young people with an ASD diagnosis Children and young people with ASD	Parents of children and young people without an ASD diagnosis
Intervention	Parent programmes that seek to increase the knowledge, skill and confidence of parents to promote the emotional well-being of their child with autism.	Parent programmes combined with another approach to intervention. Parent programmes with a focus other than emotional well-being such as behaviour or social communication skills
Study designs	Studies that explore the effectiveness of parent programmes using the criteria described Qualitative designs Quantitative designs with pre- and post-measures	Non-evaluative studies

Table 2. 2 **Inclusion and exclusion criteria for systematic review**

The results of the screening process in the review syntheses can be seen in Figure 2.2.

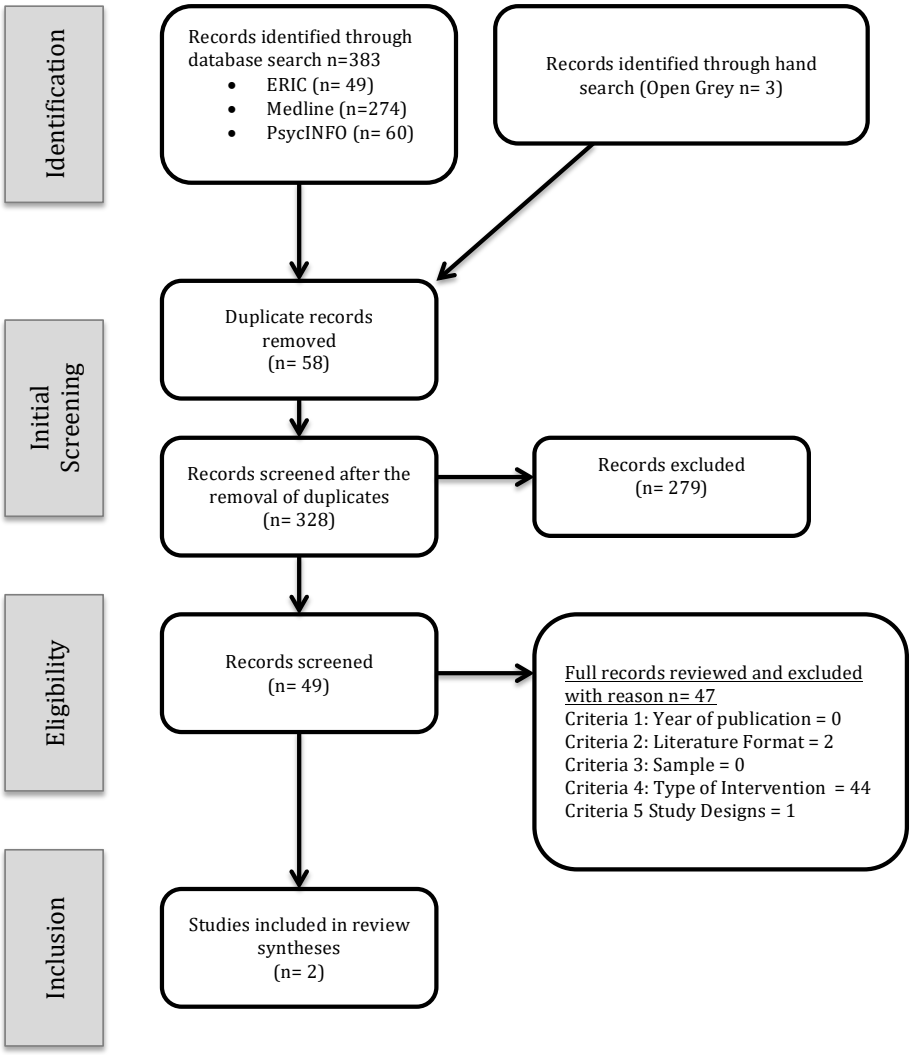

Figure 2. 2 Summary of process for review syntheses for the identification of relevant studies meeting the inclusion criteria.

2.6.5 Map of the research meeting the inclusion criteria

As shown in Figure 2.2, only two papers were identified as meeting the inclusion criteria in the systematic search. No further papers were identified meeting the inclusion criteria in a secondary search completed by the researcher, reviewing the reference list of these papers of interest.

The two studies identified in the review are summarised in Figure 2.3, providing details of the studies' aims, design, participants and findings.

Gobrial, E., & Raghavan, R. (2017)

Two phase research designing and implementing the Calm Child parent programme.

Phase one

***Aim*:** Exploration of strategies used to reduce anxiety for children with a diagnosis of autism and anxiety.

Participants: 34 participants (14 parents, 20 teachers). All participants were involved in caring for a children and young people with a diagnosis of autism and clinical anxiety.

Design: Qualitative

- Semi-structured interviews of an expert panel of health professionals used the Delphi process to converge on specific anxiety management strategies perceived to be effective in supporting children and young people with autism.

***Primary outcome*:** Ten strategies were agreed upon for inclusion in the Calm Child Programme (CCP).

Phase two

Aim: Evaluation of the Calm Child Programme in reducing anxiety in children and young people with autism.

Participants: 7 families of a child with a diagnosis of autism, mild to moderate intellectual disability and a diagnosis of anxiety.

Intervention: *Calm Child Programme.*

***Design*:** Mixed methods

- Pre - and Post – measures were taken using the Glasgow Anxiety Scale for children with intellectual disabilities (GAS-ID; Mindham & Espie, 2003).
- Parents kept a diary detailing strategies used and perceived effectiveness.

- Focus Group

***Results*:** Implementation of the parent programme CCP reduced children's and young people's anxiety levels; having a statistically significant impact on the differences captured pre- and post – measures on the GAS-ID. The monitoring diary illustrated proven effectiveness of the CCP parent programme in managing children's and young people's anxiety.

Overall outcome: Positive

Hounslow, R. (2012)

Aim: Evaluate of the Jigsaw programme against parental outcomes associated with parents' resources, the perception of stressors and hardships, and levels of stress. The impact of the programme on the child's developmental context and child-related outcomes were also explored.

***Participants*:** 12 participants in the experimental group and 4 participants in the control group. All participants had parental responsibility for a child aged 11-14 years old with a diagnosis of Autism Spectrum Disorder.

Intervention: The Jigsaw Programme

Design*:* Mixed methods

- Quasi – experimental pre- and post- measures taken using the Autism Parent Questionnaire (APQ; Anderson, Birkin, Seymour & Moore, 2006), Friedrich short form of the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg & Crnic, 1983) and The Vineland Adaptive Behaviour Scales II (VABS-II; Sparrow, Cicchetti & Balla, 2005).

- Qualitative data - Semi structured interviews.

Results: The intervention led to gains in parental knowledge and skills related to autism and results suggested participating in the programme reduced overall parental stress. A protective effect against the experience of increasingly challenging behaviour was indicated following intervention and gains in parental confidence in supporting their child's needs were also identified.

Figure 2. 3 *A summary of the studies that met the inclusion criteria of a systematic review of research.*

2.6.6 Review of the research

The reviewer appraised the studies identified in the review, considering the quality of the research and the relevance of each study to the research question. The following criteria were considered in the appraisal:

- Topic relevance to the review question - This considered the extent to which the study considered the effectiveness of parent programmes in relation to promoting outcomes linked emotional well-being in children and young people with autism.
- Trustworthiness – A judgment was made on the trustworthiness, coherence and integrity of the study. The quality of the methodology and results of each study were evaluated.
- Appropriateness – Based on the review question, the research design was considered. Both quantitative and qualitative studies were deemed appropriate to answer the research question seeking to explore the effectiveness of parent programmes as an approach to intervention to support the emotional well-being of children and young people with autism.

Gobrial, E., & Raghavan, R. (2017). Calm child programme. ***Journal Of Intellectual Disabilities*****, 174462951770453. http://dx.doi.org/10.1177/1744629517704536**

The two phases study involved the identification of strategies perceived by teachers and parents to be effective in reducing anxiety in children and young people with a diagnosis of autism and anxiety, then a panel of experts reached a consensus on appropriate strategies through a Delphi process. The strategies identified were then used to develop the Calm Child Programme (CCP) with the second stage of the study evaluating the efficacy of the approach to intervention.

The evaluative aspect of the study by Gobrial & Raghavan (2017) is considered to have high relevance to the research questions. The study focuses on evaluating the use of an intervention aimed at reducing anxiety, an outcome linked to emotional well-being in children and young people with autism.

The trustworthiness of the study is fair with aspects of the methodology presented in an explicit clear way, outlining the context, sample and analysis for the quantitative data collected. The study was published in a peer-reviewed journal, so the methodological rigour will have been subject to scrutiny. The trustworthiness would have been further supported if there had been increased transparency over the analysis of the qualitative data collected. There is no description of the method of analysis for the information captured from the focus group or daily diaries of intervention implementation, which poses a risk to the validity of the study.

The appropriateness of the study is fair, with strengths and limitations identified in the design of the study. A range of information was gathered for triangulation, participants were asked to record adherence to the programme to identify intervention fidelity and the quantitative data collected using the GAS-ID, which has been reported to have good internal consistency and test reliability for the measurement of anxiety (Mindham & Espie, 2003).

The findings of the study need to be considered in the context of the limitations of its methodology, some of which are recognised by the authors. As identified by Gobrial & Raghavan (2017), the evaluation of the CCP only involved seven families, a small sample size which has implications for the wider generalisability of the findings.

There were further limitations in the study design that were not acknowledged. In the evaluation, there was no control group for comparison of the quantitative data collected, so caution is required in attributing changes between the pre- and post-measures to the CCP intervention.

Hounslow, R. (2012). An evaluation of a locally developed psychoeducation programme for parents of young people with an autism spectrum disorder (Thesis for Doctorate of Applied Educational Psychology). University of Nottingham.

The study evaluated the Jigsaw Programme, an original psychoeducation programme for parents of adolescents with autism, a programme that considers how parents can promote the emotional well-being of their child with autism.

The study is considered to have high trustworthiness, the methodology was made explicit, outlining the context, sample, method and analysis and there were clarity and transparency of results presented. Aspects of validity and reliability were also explicitly considered in the study. As the study was submitted as a thesis for Doctoral Research the methodological rigour of the research would have been scrutinised, supporting the trustworthiness of the study.

The appropriateness of the study for the research question is deemed to be fair. The qualitative data collection involves pre- and post-test using a variety of measures. It also identified that the data measures used have been shown to have good validity and reliability. As acknowledged by the researcher, there is limited generalisability of the study's findings due to the low number of participants involved in the study and the heterogeneity of the autism group.

As the study focuses on an intervention that aims to promote the emotional well-being of adolescents and considers the effectiveness of the programme it is deemed highly relevant.

2.6.7 Review of other key studies identified

The results of the review indicate that very little research has been done into the use of parent programmes to promote the emotional well-being of children and young people with autism. As highlighted in the results of the review in Figure 2.2 studies were primarily ruled out due to the intervention used.

Studies not focusing on interventions aimed directly at promoting the emotional well-being of children and young people with autism were excluded in the review. The focus of interventions in excluded studies included: the development of parents' understanding of autism (Farmer & Reupert, 2013); the development of parents' problem solving skills (Feinberg et al., 2014); the development of parents' skills to better enable them to support the

development of their child's social functioning (Antshel et al., 2011); promoting language and communication and improving child's behaviour (Tellegen & Sanders, 2014; Dillenburger, Keenan, Gallagher & McElhinney, 2004).

In the review of existing research, there was a small body of research identified that focused on the use of interventions to promote the emotional well-being of children and young people with autism, through reducing anxiety. Where the intervention did consider the emotional well-being outcomes for children and young people with autism, the approach to intervention delivery was frequently the other reason for the exclusion of the study. These studies did not meet the inclusion criteria as they did not solely involve parent programmes as the approach to intervention. Parenting education was offered in combination with other approaches to intervention delivery. In some studies, interventions were delivered directly to the child and in others, they involved intervention delivery to both the parent and child.

Due to the limited research base to draw upon, the findings of the studies identified involving parents of children with autism targeting emotional well-being, will now be considered.

2.6.7.1 Parallel Child and Parent Interventions for promoting emotional well-being

The review of the literature did identify studies that involved interventions for the child and parent, delivered in parallel but separately. A study by de Bruin, Blom, Smit, van Steensel & Bögels (2014) evaluated the use of mindfulness training, using *Mymind* training for adolescents with autism and *Mymind* training for parents separately, in parallel. The study found the intervention reduced adolescents' rumination and improved their social responsiveness but did not reduce their worries. Parents reported feeling less reactive and more reflective following the intervention. They identified that they were better able to observe their own emotions without getting caught up in them and regulate their child's and their own emotions.

A parallel approach to intervention delivery was also used in a study by McConachie et al. (2013). Parents and their child with autism received an

adapted version of the 'Exploring Feelings' manual (Atwood, 2004), a cognitive-behavioural approach to managing anxiety separately, in parallel. The study found parents from the group who received the intervention were significantly more likely to report a reduction in the anxiety symptoms of their child compared to those in the control group. Although the studies had a wait list control, there were no comparison groups to consider the impact of delivering the intervention only to the child or parent.

2.6.7.2 Family group intervention for promoting emotional well-being

In the review of research, family focused approaches to intervention delivery were identified, aimed at reducing anxiety in adolescents with autism, with parent and their child receiving an intervention together (Hepburn et al., 2016; Reaven et al, 2011; Wood et al., 2009). The three interventions were all based on cognitive-behavioural principles using different formats of delivery.

'Facing your Fears' (Reaven et al., 2011) and a modified version of the 'Facing your Fears programme' for video conferencing (Hepburn et al., 2016) were found to be efficacious in reducing anxiety in adolescents with autism, however, as acknowledged in one study, there may have been a positive bias in parent reporting due to the time invested in the intervention (Hepburn et al., 2016).

The use of the 'Behavioral Interventions for Anxiety in Children with Autism' (BIACA; Wood et al., 2009) based on the Building Confidence CBT programme (Wood, McLeod, Piacentini & Sigman, 2009) was identified as effective in reducing autism symptom severity (Wood et al., 2015; Wood et al., 2009), however, the child reports did not yield any treatment effects (Wood et al., 2009). In contrast to the other studies, a reduction in anxiety was not consistently reflected in the measures used in the study (Wood et al., 2015).

2.6.7.3 Promoting parental emotional well-being and mental health

It is well known that parent mental health and well-being has an impact upon that of their child. In the review of research, parent programmes aimed at promoting parents well-being were identified (Ji, Sun, Yi & Tang, 2014; Neece, 2013). Parent education programmes have been found to be an efficacious

approach for caregivers with children with autism in reducing family problems, improving positive coping style, parenting self-efficacy and improving mental health quality of life indicators (Ji, Sun, Yi & Tang, 2014) and reducing parent stress and mental health problems (Neece, 2013). Parental self-esteem and perceived parenting competence were also found to be enhanced through a parent programme focusing on behaviour (Dillenburger, Keenan, Gallagher & McElhinney, 2004).

2.6.8 Reflections on the search strategy used to identify research

The quality of the search strategy used in a systematic review determines what items are identified and missed. In the current study, the search criteria aimed to be sensitive to identify potentially relevant literature, while seeking to achieve specificity, to identify literature specifically relevant to the current study. The researcher made the decision to incorporate terms clearly related to autism as this potentially vulnerable population was of specific interest in this study. It is however acknowledged that by doing this it could narrow the results of the review, and literature relating to the use of parent programmes to children and young people's emotional well-being was not identified.

To maximise the retrieval of the search in the review some synonyms were used to broaden its range, considering variations of how the topic may be described by other researchers. For example, when exploring parent education synonyms were used which included: *parent training*, *parent intervention*, *parent psychoeducation*. It is recognised that the search could have been further widened, by including adding additional search terms. For example, emotional well-being is a broad concept and as discussed in section 2.5.1, one encompassing many related facets. Including additional terms such as depression and mental health may have may have influenced the results found and this is recognised as a limitation of the current review.

2.6.9 Summary

Parental involvement in programmes to promote emotional well-being has demonstrated some positive outcomes for parents and their children. When

parents have been involved in the delivery of intervention in parallel or as part of a family group, it has been demonstrated to be an efficacious approach to reduce anxiety symptoms, autism symptoms and promote parental sense of efficacy and competence.

Only two studies were identified that focused on the use of a parent programme to promote the emotional well-being of a child or young person with autism, using the search strategy employed. The use of parent programmes was found to have positive outcomes for parents (Gobrial & Raghavan, 2017; Hounslow 2012) and their children (Gobrial & Raghavan, 2017). As discussed, both the studies identified were of fair quality, however due to the limitations of the studies and the lack of research in this area, it is not possible to draw any conclusions about the potential of the use of parent training alone as an approach to intervention to promote the emotional well-being of children with autism. As the outcome indicators are positive, it highlights a need for further research into the potential of this approach.

2.7 The Research

2.7.1 Rationale for the research

The previous sections have provided an overview of autism and have identified the large number of people in UK affected by autism. Given the prevalence, a significant number of adolescents in the UK will be living with autism. The potential challenges of the adolescent years have been discussed, and it has highlighted how these can be particularly difficult for those individuals with autism. Research indicates that due to the difficulties people with autism experience, they are at increased risk of poor outcomes associated with emotional well-being and the negative associated impact. As identified, mental health difficulties significantly increase in adolescence (de Bruin et al, 2006). These findings highlight a need for early intervention and prevention work to promote the emotional well-being for children and young people with autism.

Research indicates parent education programmes have been an efficacious approach that has been widely used to support children and families with autism. There has been little research into the use of parent education programmes to support the developmental needs of children with autism as they grow older and the challenges and demands change.

Specifically there is limited research on the use of parenting programmes to promote the emotional well-being of children and young people with autism. Currently, only two research papers have been identified that specifically use parent programmes as the sole approach to intervention to promote children and young people's emotional well-being. Positive findings in these studies highlight the potential for using this approach and this research seeks to further contribute to the evidence based in this area.

The Autism, Emotional Well-being and Adolescence (AEWA) programme is an original programme that has been developed to promote the emotional well-being of adolescents with autism. The programme is currently offered by the EPT in a LA and therefore the programme is accountable for the cost invested by all the stakeholders involved, which may be financial, time or personal. An

evaluative research project therefore can assess the efficacy of the project and ensure it is effective in supporting positive change in the knowledge and confidence of those who participate in the areas the intervention programme targets.

The AEWA parent programme aims to increase the knowledge and confidence of parents of children and young people with autism. It focuses on emotional well-being and the potential influences on it during adolescence, highlighting approaches parents can use to support their child.

This research aims to explore the effectiveness of a programme in achieving the intended outcomes through addressing the research questions outlined.

2.7.2 Research questions

- *Does the Autism, Emotional Well-being and Adolescence programme change parents' perceived knowledge and understanding of emotional well-being, potential challenges in adolescence and how they can support their child with autism?*
- *Does the Autism, Emotional Well-being and Adolescence programme change parents' perceived confidence in promoting the emotional well-being of their child with autism through potential challenges in adolescence?*

Due to the limited research in the area of parent programmes in adolescent children, the second phase of the investigation is exploratory to help understand the experience of parents, both during and as a result of attending the programme. This information can be used to help inform and improve the programme to better meet the needs of the target group.

- *What are participants' reflections of their experience of attending the Autism, Emotional Well-being and Adolescence programme?*
- *What are participants' subsequent experiences as a result of attending the Autism, Emotional Well-being and Adolescence programme?*

Chapter 3 - METHODOLOGY

3.1 Introduction to the section

This purpose of this study is to undertake real-world research to evaluate the Autism, Emotional Well-being and Adolescence (AEWA) programme. This section considers the study in the context of 'real-world' and 'evaluation' research. It discusses the dominant research paradigms that are relevant to this study and positions the researchers in relation to their epistemological, ontological and methodological stance providing a rationale for the design of this study. An overview of the design is then provided.

Ethical considerations in relation to stakeholders are also considered in this section before it is concluded with a detailed summary of the intervention of focus in this study, the AEWA programme.

3.2 Real-world research and evaluation research

Real-world research is concerned with solving problems. It often has a people dimension and focuses on challenges, understanding them and seeking ways to overcome them (Robson, 2011). This study is viewed as 'real-world' research, as it focuses on an intervention that seeks to address the challenge of how to promote the emotional well-being of the child with autism, specifically through the potential challenges of adolescence.

Real-world research often explores, describes and/or explains phenomena. It is often used for evaluation purposes, which can be used to identify the effectiveness and appropriateness of the use of resources (Robson, 2011; Cohen, Manion & Morrison, 2011). Evaluation research can uncover a need for change, while the information generated can be used to inform developments and make improvements to the subject of the evaluation (Robson, 2011). Therefore, evaluation research has been identified as being intertwined with power and politics, as it can be used to inform political decisions about priorities and directions (Greene, 2000; Cohen et al., 2011).

Evaluation research supports the development of evidence-based practice, as findings from this type of research can be aggregated through meta-analysis, and used to inform practice (Gulliford, 2015). In psychology, the purpose of evidence informed practice is to enhance outcomes for individuals through the use of empirically supported practices to promote effective psychological assessment, case formulation, therapeutic relationship and intervention (APA, 2006). Evidence-based practice is important for reasons of accountability and ensuring no harm is done.

In determining evidence-based practice, a 'hierarchy of methods' has been used to determine what constitutes evidence (Roth & Fonagy, 1996). This has privileged methodological approaches underpinned by positivist approaches, with systematic reviews and randomised control trials (RCT) identified as the most valid and reliable evidence. In contrast, it has been argued that the use of RCT in social sciences is not appropriate for dealing with the complexity of social issues (Pawson & Tilley, 1997). Within the profession of educational psychology, the 'hierarchy of methods' has created both consensus and disagreement (Burnham, 2013). Views on what counts as credible evidence in applied research and evaluation studies are rooted in the paradigm debate, influenced by the ontological, epistemological and methodological assumptions that anchor views.

This evaluation study seeks to explore the effectiveness and appropriateness of the AEWA programme, as a parent intervention. It is anticipated that this study will contribute to the evidence base and will be used to inform areas for development in the programme, if a need for change is identified.

Evaluation research can make use of a range of designs; those chosen are informed by the paradigm adopted by the researcher. The following section discusses the paradigms that have been identified as most relevant to this evaluative research.

3.3 Research Paradigms

Developing research involves the intersection of research philosophy, research

design and specific methods, requiring the researcher to consider their philosophical worldview when undertaking research (Cresswell, 2014).

The term 'paradigm' is often a term associated with worldview, however it does have different conceptualisations, such as epistemological stance or shared beliefs amongst members of a speciality area. Yet, underpinning all the different conceptualisations, is the understanding that 'paradigm' reflects a system of shared beliefs and practices (Morgan, 2007).

Lincoln and Guba (2005) compare differing paradigms considering the associated ontological, epistemological and methodological positioning, which they describe as fundamental differentiating axioms. Ontology describes the philosophical view of the nature of reality or being, which can be viewed as subjective or objective, while epistemology describes the nature of knowledge and how it is created. The procedures used for gaining knowledge are described as the methodology.

The metaphysical paradigm used by Morgan (2007) to describe the work of Lincoln and Guba (1985, 1988) implies a researcher's ontological stance will inform their epistemology and subsequently their methodology. This position suggests combining methods typically aligned with different paradigms "*is impossible*" (Guba, 1990, p.81).

Overviews of the ontological, epistemological and methodological positions of the main paradigms guiding the design of this study are discussed further in the following sections.

3.3.1 Positivism and post-positivism paradigm

Positivism refers to beliefs about how legitimate knowledge can be acquired (Willig & Stainton Rogers, 2017). Underpinning the positivist view are the assumptions that the social world can be studied in the same way as the natural world, with a single external reality existing that is separate from the researcher description (Mertens, 2015). Positivist research seeks to create scientific knowledge about this reality, which is objective and value-free; suggesting only this type of knowledge is valid.

Post-positivists seek to overcome some of the criticisms of positivism while maintaining some of the central tenets. Post-positivism acknowledges much of the human experience is not observable; with positivism leading to a narrow view of studying only what is observable. Post-positivists are committed to an objectivity reality, but argue there can be multiple coexisting interpretations of the reality (Cohen et al., 2011). It is acknowledged that what is observed by the researcher is influenced by the characteristics and perspective of the observer (Mertens 2015). Research from this position seeks to uncover the truth not with certainty, but instead from what can be known imperfectly, with probability (Robson, 2011).

Within the positivism and post-positivism paradigm there is a preference for predominantly quantitative methods. Randomised control trials (RCT) are considered as the gold standard in methodological rigor in quantitative research to develop evidence-based practice. However, as highlighted it has been claimed that the use of scientific methods is often not possible or appropriate in real-world research when dealing with complex social issues (Pawson & Tilley, 1997). As a result, quasi-experimental methods aligned to post positivism that involve experimental approaches without the random allocation to groups, have developed and are widely accepted (Mertens, 2015).

3.3.2 Constructivism

The underpinning ontological assumption of the constructivist paradigm rejects the post-positivist view of a single objective reality; instead it views reality as being constructed through interactions (Mertens, 2015). Constructivism views knowledge as something that is not discoverable, but instead constructed (Schwandt, 2000), with individuals making sense of their world and attaching meaning through their interactions and interpretations (Robson, 2011). Therefore, from a constructivist perspective, the aim of undertaking research is to attempt to understand the complexity of lived experience by those involved in the research and, instead of seeking objectivity, the focus is confirmability, which is when the product of inquiry is without bias (Lincoln & Guba, 2000).

A researcher's own personal, cultural and historical experiences will shape the interpretations they make so the researchers need to recognise their own position in the research (Creswell, 2014). Therefore, the researcher should share their frame of reference, which they are using to undertake their research (Cohen et al., 2011).

The use of qualitative methods dominates the constructivist paradigm, which supports access to the interactions between the researcher and the respondents in which reality is created (Lincoln & Guba, 2000).

3.3.3 Pragmatic approach

Pragmatism views a paradigm as representing a system of shared beliefs as opposed to an epistemological stance, rejecting Lincoln and Guba's metaphysical conceptualisation of a paradigm. Pragmatism contrasts other paradigms, shifting the focus from philosophical debates about ontology and the nature of reality, to the research problem (Morgan, 2007; Tashakkori & Teddlie, 2010; Creswell, 2014). The purpose of research from a pragmatist stance is to identify what works and possible solutions to the research problem (Patton, 1990), with the methodology being central to influencing the research design. Pragmatism does accept the relevance of epistemology but rejects privileging ontological assumptions in the top-down approach that subsequently constrains epistemological assumptions and methodology (Morgan, 2007).

The pragmatist approach can accept both the view of a single 'real-world' and that it is open to individual interpretations influencing how it is experienced (Mertens, 2015). Questions asked in research are not inherently important but are identified as such by the researcher. What is chosen is influenced by their personal history, social background and their cultural assumptions, so it is important researchers remain reflexive in what is studied and how it is done (Morgan, 2007).

Pragmatism views the purpose identified in research questions as central, with appropriate designs determined by those that best answer the questions considering the research context (Hesse-biber & Johnson, 2013). Pragmatists

seek to consider the effectiveness as to whether something worked in relation to solving the problem focused on by the researcher (Mertens, 2015). Pragmatism has no allegiance to any one methodology; therefore, quantitative or qualitative methods are compatible and those that are chosen are identified as providing the relevant knowledge to address the research problem.

A pragmatic stance has been adopted in the design of this study, with methods chosen on what will best answer the research questions. As argued by Johnson & Onwuegbuzie (2004), taking a pragmatist stance in this study provides a practical outcome orientated approach, which can combine methodological approaches to gain a deeper insight. This approach, privileging research questions over methods and procedures, is well aligned with the work of an educational psychologist (Burnham, 2013).

Pragmatism has been identified as a suitable philosophical partner for mixed methods research (Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2010). The mixed method approach and its application to this study will now be considered.

3.4 Mixed Methods

Mixed methods have been defined as one of three main methodological approaches along with quantitative and qualitative approaches (Johnson, Onwuegbuzie & Turner, 2007). Mixed method research involves investigating the same underlying phenomenon in one study through the collection, analysis and interpretation of data using both quantitative and qualitative methods (Leech and Onwuegbuzie, 2009). The mixed methods approach can be implemented at all levels of research, from the philosophical stance guiding the research, the methodology and the method for data collection, interpretation analysis and reporting (Cresswell & Tashakkori, 2007).

In conducting mixed method research there are different possible designs that can be used, with researchers making decisions about the most appropriate design for their study (Creswell, 2014). In mixed methods designs, there are three primary approaches that include: convergent parallel mixed methods;

explanatory sequential mixed methods and exploratory sequential mixed methods (Creswell, 2014). Convergent designs involve the collection of qualitative and quantitative data concurrently, which may be done separately or alternatively can be embedded or nested together. Results can then be considered separately and compared for convergence or integrated for interpretation; priority may be given to the results of one method. Sequential designs involve the initial use of either a quantitative method in explanatory designs or qualitative methods in exploratory designs. This is then followed by the alternative method of data collection. Priority can be given to the results of one method and can be interpreted independently or together.

A mixed methods design for this study was chosen. As noted by Greene et al (1989), using mixed methods provide an opportunity to triangulate data captured to see if there is cooperation and convergence in the findings. Combining methods in this study will also provide an opportunity to gain a broader perspective of participants' views, expanding the breadth of the inquiry components that can be explored to meet the overriding research aim of evaluating the AEWA programme.

As discussed by Johnson and Onwuegbuzie (2004) using mixed methods utilises the strengths of both quantitative and qualitative methodologies. In this study, the use of a quantitative approach will support credibility in assessing cause and effect relationship of the intervention on participants' knowledge and confidence. This will then be complimented by the qualitative approach, that will provide a rich thick description to support an understanding of individuals' shared experiences of the AEWA programme.

3.5 Summary of the chosen design

This study adopts a pragmatic approach, with the primary priority of utilising research methods that best answers the research questions. A mixed method, convergent design, is used that combining both quantitative and qualitative methods. Data will be collected in parallel, analysed separately and the results will be considered both separately and then together.

Chapter 4 provides an overview of the explanatory aspect of the study, detailing the quantitative quasi-experimental design that will assess the impact of the AEWA programme on parents' perceived knowledge and confidence to promote the emotional well-being of their child with autism, while supporting them through adolescence. The exploratory aspect of the study is then detailed in Chapter 6, which addresses the research questions about the experiences participants had whilst on the programme and subsequent experiences as a result of attending the programme.

3.6 Validity and reliability

In quantitative and qualitative approaches to research, the terms validity and reliability have different meanings, which influences the principles used to address these issues. Cohen, Manion & Morrision (2011) highlight the importance of researchers demonstrating fidelity to the principles of their chosen approach when addressing issues of validity and reliability in research. As this study uses mixed methods, drawing on quantitative and qualitative approaches, issues of validity and reliability for each will be addressed separately, guided by the principles of each approach and will be discussed in the appropriate sections.

3.7 Ethical considerations

This research adheres to ethical guidelines and considerations provided by the British Psychological Society Code of Human Research Ethics (BPS, 2010), the Health Care Professionals Council's Guidance on Conduct and Ethics for students (HCPC, 2016) and the University of Nottingham Research Committee's Code of Research Conduct and Research Ethics (University of Nottingham, 2013). Ethical risks and the protocol of how they were managed are summarised in Table 3.1.

Ethical approval for the research was gained from the University of Nottingham in April 2017 (Appendix A).

Possible Risks	*Risk Management Protocol*
Effects of participating in research	Participation in the intervention programme was entirely voluntary. As individuals would access the programme, irrelevant of the research, the risk was viewed as minimal. Support was available from members of the educational psychology team (EPT) delivering the programme if any content of the programme caused distress. Completion of the quantitative measures and participation in the semi-structured interviews involved personal reflection on potentially sensitive emotive topics. All participants were provided with details of local and national organisations from which they could receive support and they were encouraged to access support where deemed appropriate.
Allocation to experimental and control	The researcher was not involved in the allocation of individuals to the AEWA programmes. Allocation to was done following the EPT's procedures. A pragmatic approach was used to allocate participants to the experimental and control group. The first programme ran in summer 2017 and was used to gain participants for the experimental group and the following programme was used to gain participants for the control group.

Consent	An overview of the research and its purpose was provided to all participants in a written information sheet (An example can be seen in Appendix B). A verbal explanation was also provided by the researcher in person or over the telephone who was available to answer questions, prior to gaining consent. It was made explicit in writing and verbally that there was no requirement to take part in the research and participation in the programme was not contingent on participation in the research. Written consent was gained prior to individuals participating in the research; these were retained by the researcher. Verbal consent to audio record interviews was also gained at the start of the interviews.
Right to withdraw	The right to withdraw without reason was made explicit to participants and this was highlighted on the consent form.
Deception	Participants were informed of the aims of the research and were not deceived at any point in the research.
Confidentiality	To ensure anonymity, no identifiable details were recorded on the questionnaire. A coding system to identify individual's data for comparison was used. Consent forms and details of the linked codes were stored securely separately from the data collected. All efforts were made by the researcher to ensure that participants involved in the qualitative study were not identifiable in the data analysis and write up.
Dissemination	Dissemination of the studies findings to all the stakeholders upon completion of the research.

Debriefing	Participants were provided with the opportunity to raise any questions or concerns after the research. Facilitators of the AEWA programme from the EPT were available during and after the programme to offer support. Participants receive a letter thanking them for their participation in the research and providing a summary of the research findings upon completion of the research.

Table 3. 1: Ethical consideration and protocol implemented to minimise the risks to the study

3.8 The Autism, Emotional Well-being and Adolescence programme

To support an understanding of what is being investigated in evaluative research, a detailed description of the intervention of focus is required. This also allows researchers to replicate and build upon findings (Hoffman et al., 2014). Using the guidance provided by the template for intervention description and replication (TIDieR) checklist, this section seeks to describe some items identified to provide a detailed overview of the intervention.

3.8.1 Name of the intervention

The intervention evaluated in this study is the Autism, Emotional Well-being and Adolescence programme (AEWA), developed for families of children with autism.

3.8.2 Rationale for the intervention

The programme was conceived and developed by an EPT in a local authority (LA) setting as a way to utilise psychological knowledge and evidence-based practices to support parents to meet the needs of their children with autism.

The programme was designed for parents of children with a confirmed diagnosis of any condition falling under the umbrella of Autism Spectrum Disorder. Children and young people with autism have increased risk of poorer emotional well-being compared to their typically developing peers (The Department for Education, 2016). The AEWA programme was developed to take a proactive, preventative approach by preparing parents with the provision of information about promoting emotional well-being and the potential challenges of adolescence. The programme was aimed at parents of children who were pre-adolescent or in the early stage of adolescence, aged 8-13 years old.

As previously discussed in section 2.5.9, it is known that improving or extending parents' understanding and knowledge about child development supports parent programmes to be effective. The AEWA programme focuses on developing an understanding of child development with a focus on emotional well-being and the potential challenges in adolescence, which can potentially

affect well-being. It has a particular emphasis on how the needs typically associated with autism may interact and influence a young person's development through this life phase.

3.8.3 Material used in the delivery of the intervention

The information delivered in the AEWA programme is presented using PowerPoint and multimedia clips. Participants are provided with a copy of the slides at the start of the session and activities to support participants' learning are integrated throughout the programme. During the programme, facilitators signpost participants to a range of multimedia resources, books and support groups related to the areas covered, while encouraging participants to share those they are aware of.

3.8.4 Procedure for intervention delivery

The EPT was responsible for the recruitment to the AEWA programme. The programme was aimed at parents of children aged 8-13 years old, with a confirmed diagnosis of any of the conditions falling under the umbrella of Autism Spectrum Disorder.

The AEWA programme was split into six modules, an overview of the module aims and content can be seen in Figure 3.1.

Modules	*Aims of the module*
Module 1 **Autism and anxiety**	▪ To develop an understanding of what anxiety is ▪ To highlight the links between anxiety and ASD ▪ To raise awareness of signs of anxiety ▪ To consider the links between feelings and behaviours ▪ Raise awareness of approaches and strategies to support young people to identify and share feelings
Module 2 **Autism and anxiety**	▪ Develop an understanding of approaches to promote emotional wellbeing
Module 3 **Developing resilience in children.**	▪ To develop an understanding of resilience and how to build it ▪ To consider how we can support emotional understanding ▪ To consider how we can support self-esteem
Module 4 **Developing resilience in adults.**	▪ To understand the link between adult emotional wellbeing and child emotional wellbeing ▪ To identify strategies to support resilience in adults ▪ To consider the impact of role models, helping others and support networks
Module 5 **Coping with Adolescence**	• To consider the impact of adolescence for young people on the autism spectrum ▪ To develop an understanding of sex and relationship education for young people on the autism spectrum ▪ To share successful strategies

Module 6 **Transitions and promoting independence**	▪ To consider transitions in adolescence ▪ To develop an understanding of how young people on the autism spectrum can be supported to make positive transitions ▪ To consider how independence can be promoted in young people on the autism spectrum

Figure 3. 1 Overview of the module aims and content of the Autism, Emotional Well-being and Adolescence Programme

The AEWA programme was developed incorporating elements of what is known to promote the effectiveness of parent programmes, as identified in section 2.5.8. The programme has clear aims as illustrated in figure 3.1, with a structured approach to content delivery to support the achievement of the aims. Within the programme, facilitators seek to create an environment that is supportive and non-judgmental, in which parents are valued and encouraged to be active partners in the programme. Parents are encouraged to participate in the programme and are encouraged to share their stories and experiences. Providing frequent opportunities for discussion and group work in which empathetic listening and talking through challenges with one another is encouraged, facilitating the provision of social support in the programme.

The content of the AEWA programme includes anticipatory guidance throughout; with facilitators identifying a range of evidence-based approaches that parents can try to support their child's development in adolescence. The effectiveness of parent programmes is supported by a strong theoretical base (Whitacker & Cowley, 2010). The content of the AEWA programme developed a diverse range of psychological theory and theoretically informed interventions tailored to meet the needs of parents of children with autism. Through the provision of information on the programme, the aim of the programme is to develop parents' knowledge of particular topics, as well as knowledge of potential strategies to take away and use, so they are better able to promote the emotional well-being and behavioural adjustment of their child with autism.

The content of the AEWA programme is underpinned by insights gained from resiliency theory. As discussed in section 2.3.4, promoting resilience is a mechanism in which emotional well-being can be promoted (Mguni, Bacon & Brown, 2012).

During the initial modules, the programme starts with a focus on emotional regulation, which has been found to be a protective factor to promote resilience. Insights are shared from cognitive-behavioural psychology to help develop an understanding of how thoughts and feelings underpin behaviours. Evidence supports the use of psychosocial interventions through cognitive behavioural approaches to develop emotional regulation in children and young people with autism to promote well-being (Reaven et al., 2011; Clarke etal., 2016; Luxford, et al., 2016; Slack, 2013; Barrett, 2010). In the programme, the thoughts, feelings and behaviours behind different emotions are explored, with a specific focus on anxiety and anger. Techniques based on cognitive behavioural approaches are then considered to promote parents' knowledge and skills in how they can promote their child's emotional well-being.

The programme then moves on to focus explicitly on resiliency theory, with a framework for resilience shared with participants. Ways to develop other protective factors in children, such as building self-esteem are then explored. As part of the programme, attention is specifically given to building the resilience of parents so they are better able to support their child. From an interactionist perspective, this is important given the significant impact autism can potentially have on parents' stress, parenting self-efficacy and physical and mental health (Place, 2016; Karst & Van Hecke, 2012; Rao & Beidel, 2009).

The final modules in the AEWA programme, provide information to promote an understanding of child development with a focus on adolescence. Information about key topics associated with adolescences is given and discussed, which include: sex and relationships, transition and promoting independence. As discussed in section 2.4, such topics are particularly relevant as they pose a potential challenge in adolescence, with the needs associated with autism making them pertinent. Through developing parents knowledge and

understanding it is anticipated that parents can be proactive and take preventative action to promote their child's emotional well-being during this phase of development.

3.8.5 Intervention provider

The AEWA programme is delivered by two qualified educational psychologists (EPs), employed by a local authority. The EPs delivering the programme used in this study had completed the doctoral training in applied educational psychology. Both EPs were experienced and had been involved in the development of the AEWA programme.

3.8.6 Model of intervention delivery

The AEWA programme was delivered as a group intervention. Each AEWA programme typically has places for twelve families. Parents are invited to attend, with a parent defined as the main carer for the child who has parental responsibility. To encourage a consistent approach to supporting children with autism, parents who took a place on the programme are offered the opportunity to invite secondary participants to attend with them, which could be another carer for their child. A professional from the child's educational setting is also invited to attend the programme with the parent. Details of the participants attending the AEWA programme from which data was collected can be seen in section 4.2.4.

3.8.7 Location of intervention delivery

The AEWA programme was delivered in conference venues. Participants are invited to the programme delivered in their geographically closest venue.

3.8.8 Structure of delivery

The AEWA programme is delivered over three days, one day a week, bi-weekly. The AEWA programme is split into six modules; with each module allocated approximately two hours fifteen minutes for delivery. Two modules were delivered a day with a short lunch break in between modules.

3.8.9 Tailoring of the intervention

Participants were encouraged to engage in activities throughout the programme, to facilitate the sharing of their own personal experiences and knowledge. As participants needs are identified in the group these are responded to by the group and the EPs facilitating the intervention delivery, drawing on their professional knowledge. It is therefore recognised that despite the manualised approach to support delivery of the AEWA programme, not all participants receive an identical intervention as participants vary across programmes.

3.8.10 Fidelity of intervention delivery

The AEWA programme is manualised with detailed notes, slides and activities to support intervention fidelity. The fidelity of the intervention delivery for the programme of focus in this study is detailed in section 4.3.2.

3.9 Summary

This section has positioned this study as real-world, evaluative research. It has identified the pragmatic stance adopted by the researcher and the use of mixed methods to guide data gathering, analysis and interpretation to best answer the research questions identified as important in evaluating the AEWA programme. An overview of the intervention has been given highlighting key aspects of the AEWA programme. The following chapters will separately detail the quantitative and qualitative methods used in this study.

Chapter 4 - QUANTITATIVE DESIGN

4.1 Introduction to the section

As discussed in the previous section a quantitative design is used to explore the causal relationship between the AEWA programme and parents' perceived knowledge and confidence to support the emotional well-being of their child with autism. It also explores the causal relationship between the AEWA programme and parents' perceived knowledge and confidence to help their child with autism through the potential challenges of adolescence.

This section provides an overview of the participants involved in this study and how the sample was secured. The section then goes on to provide details of the experimental condition, including details of the intervention delivery and the approach to data collection. A bespoke measure was developed for use in this study, so the rationale for doing this is discussed and how it was done is illustrated. Issues of the validity of the quantitative design are then addressed before this section is concluded with details of the statistical analysis used in the study.

4.2 Participants

4.2.1 Inclusion criteria

Parents given a place on the AEWA programme by the EPT were identified as potential participants for this study. Although parents were able to invite another caregiver for their child and educational staff, to ensure the study was manageable in the timeframe available, this study only included parents.

4.2.2 Sampling

Sampling procedures influence the quality of research and the inferences that can be made from research finding (Robson, 2011). To support the external validity and generalisability of findings, the use of probabilistic sampling (also known as representative sampling) is preferable, however, in real world research, this can be extremely difficult and often unobtainable (Robson, 2011).

The population of interest in this study is the parents of children aged 8-13 years old, with a diagnosis of autism. A self-selecting, non-probability sample of this population was used in this study.

Parents expressing an interest in attending the programme, who met the eligibility criteria, were offered a place on their geographically closest programme, on a first come basis. Parents were sent a letter with a brief overview of the evaluation research and an invitation to participate (Appendix C) with the letter confirming their place on the AEWA programme. Those interested in participating in the research consented to be contacted by the researcher by returning a form in a pre-paid envelope or by emailing the EPT.

Random allocation of participants to groups is argued to be the gold standard in experimental research (Robson, 2011). This was not deemed feasible as the two AEWA programmes were run in different areas of a large county and the programme participants were spread over a large geographical area. As suggested by Campbell and Stanley (1963), when random allocation is not possible, a quasi-experimental pre- and post-test, non-equivalent group design (non-random group allocation) is considered an appropriate alternative. Participants were therefore allocated to the experimental group and control group, based on the timing of the AEWA programme they attended. Those attending the summer 2017 programme were allocated to the experimental group and those given a place on the autumn 2017 programme were allocated to the wait-list control group. An overview of the recruitment of the sample in both the experimental and wait-list control group can be seen in Figure 4.1.

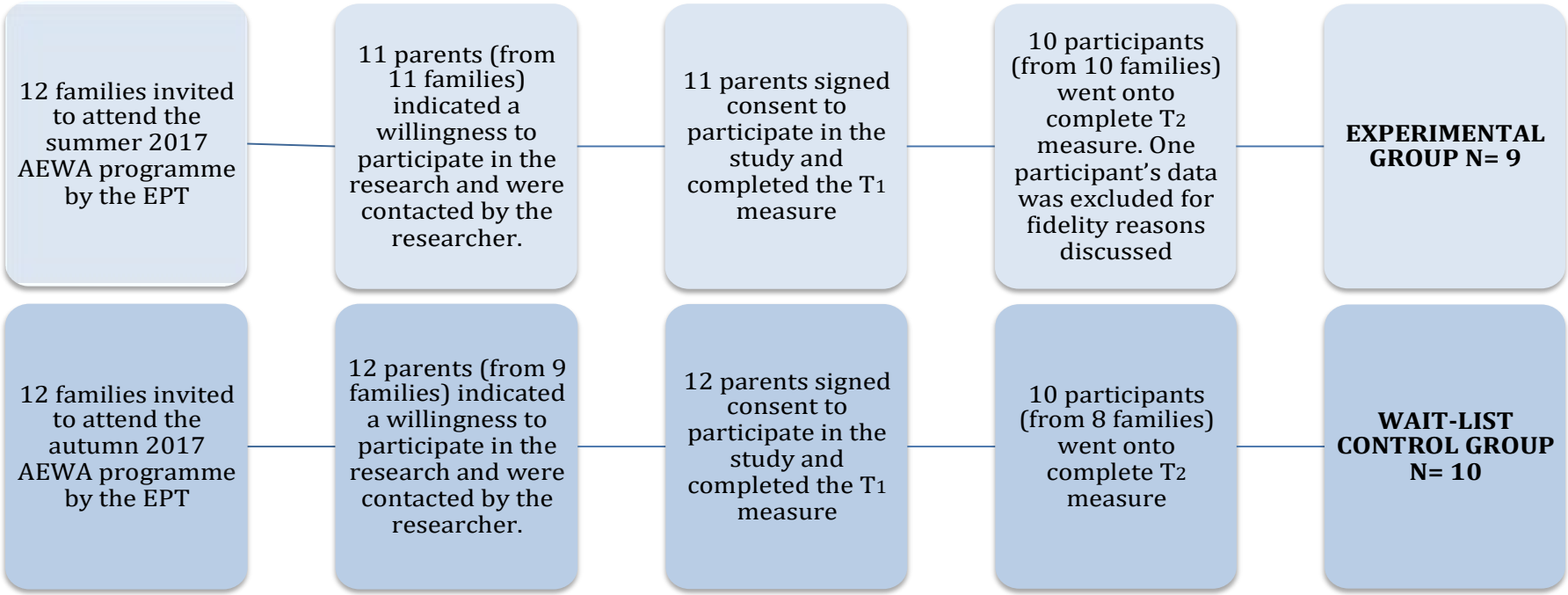

Figure 4. 1: *Overview of the sample recruitment for the experimental group and wait-list control group*

The researcher contacted all potential participants invited to attend the summer and autumn programmes who had indicated an interest in being involved in the research by telephone. The researcher clarified details of the study and what was involved in participating, and opportunity to ask questions was also provided. Those who confirmed they wished to be involved were sent the informed consent forms (Appendix D), participant information (Appendix B) and the pre-intervention (T_1) measures (Appendix E).

4.2.3 Sample size

In exploring the effectiveness of an intervention, the sample size used in research designs affects the likelihood of identifying a statistically significant result if the intervention is effective. It is also has implications for the external validity of the study with a large sample size reducing the error in generalising findings (Cohen et al., 2011). When undertaking statistical analysis in quantitative research, it is widely accepted a minimum sample size of 30 participants is identified, although many more participants are often recommended (Cohen et al., 2011). Formulaic determinations of sample size can be used to ensure there is an adequate sample size to identify any effects that exist. Onwuebgbuzie, Jiao and Bostick (2004) calculated a recommended sample size of 21 participants per group for significance testing for experimental and quasi-experimental research using Cohen's (1988) criteria for identifying a medium effect of 0.80 power, at the 5% level of significance size.

This real-world research was subject to time and funding constraints, which meant it was not possible to secure the preferred sample size. If one-hundred percent of parents attending the programme had agreed to participate in the study, the sample size would not meet the minimum recommended as there was only a maximum number of twenty-seven potential participants across the two programmes. Due to the constraints on the research, it was not feasible to extend the number of programmes to meet the minimum number of participants. The study formed part of the researcher's requirements for the Doctorate in Applied Educational Psychology, a programme of study that is time bound. The LA also only agreed to fund the delivery of two AEWA programme in

2017, with places on each programme for parents from 12 families. Given the small non-probabilistic sample available, the results will be interpreted with caution.

4.2.4 Description of participants

Details of the participants in the experimental and control group can be seen in Table 4.1. Mothers predominantly attended the AEWA programme, but fathers also attend the programmes. The participants in the study represent the disproportionate number of mothers who attended, with only two fathers participating in both the experimental and wait-control group.

Details of the characteristics of participants' children were gathered in the T_1 measure. All parents in the experimental group were from different families. One parent identified she was supporting two children with autism. Consequently, the experimental group, participants identified they were supporting a total of ten children with autism. In the control group, there were two instances of two parents from the same family completing the measures, so were associated with the same child. These parents were asked to complete their measures independently, without discussion. Consequently, in the control group, participants identified they were supporting a total of eight children with autism. An overview of the characteristics of all the participants' children with autism can be seen in Table 4.2.

Participants were asked to identify any intervention they had accessed from any other services, historically and concurrently. As it can be seen in Table 4.3, a range of different services had been accessed by participants in both the experimental and control group. A small number of participants in both groups (two in the experimental group and three in the wait-control group) identified they were receiving or had received psychoeducation other than the AEWA programme. Some participants in both groups had involvement from the EPT historically, with one participant in the experimental group and two participants in the wait-list control group reporting on-going involvement at the time the T_1 measure was taken.

	Relationship to child		Age			Level of Education				Employment status				Number of children			
	Mother	Father	30-49 years old	50-64 years old	65+ years old	Level 2 or equivalent	Level 3 or equivalent	Degree or equivalent	Postgraduate	Unemployed	Part-time	Full-time	Retired	1 Child	2 Children	3 Children	4 Children
Experimental Group - N	7	2	8	-	1	2	4	1	2	6	1	1	1	3	4	2	-
	78%	22%	89%		11%	22%	11%	44%	22%	67%	11%	11%	11%	33%	44%	22%	
Wait Control Group - N	8	2	9	1	-	3	4	-	2	1	6	3	-	1	6	1	2
	80%	20%	90%	10%		30%	40%		20%	10%	60%	30%		10%	60%	10%	20%

Table 4. 1 Summary of participants' characteristics

	Gender		Mean Age (Range)	Approximate mean time since diagnosis (Range)	Other diagnosis in addition to autism
	Female	**Male**			
Experimental Group	3	7	10.5 years old (8-13)	4 years	5
Wait-list Control Group	3	5	10 years old (9-12)	2.7 years	3

Table 4. 2: Summary of the characteristics of the participants' child with autism

	Psychology			**Education**		**Health**					**Care**	**Other**		
	Educational psychology	**Clinical Psychology**	**Psycho-education Programmes**	**School Staff**	**Autism Outreach**	**Medical professional**	**Speech and Language**	**Occupational Therapy**	**Physiotherapy**	**CAMHS**	**Social Care**	**Other professionals**	**Charities**	**Social Groups**
Experimental group														
Current involvement - N	1 11%	-	-	8 89%	2 22 %	4 44%	-	-	1 11%	1 11%	2 22%	1 11%	-	8 89%
Historical involvement - N	2 22%	1 11%	2 22%	1 11%	5 56%	3 33%	4 44%		1 11%	1 11%	1 11%	2 22%	-	1 11%
Wait-list control group														
Current involvement - N	2 20%	1 10%	1 10%	9 90%	4 40%	1 10%	1 10%	-	-	1 10%	1 10%	1 10%	2 20%	2 20%
Historical involvement - N	5 50%	2 20	2 20%	2 20%	3 30%	2 20%	5 50%	1 10%	1 10%	2 20%	1 10%	2 20%	1 10%	1 10%

Table 4. 3 Summary of participants' receipt of historic and current interventions.

4.3 Experimental condition

4.3.1 Intervention delivery

The intervention focused upon in this study is the AEWA programme, which is described in section 3.8. The summer 2017 programme was led and facilitated by two senior educational psychologists (EPs) employed by the EPT. Both EPs had been involved in developing the programme. The programme ran one day a week for three consecutive weeks. Two modules were delivered each day, with each module lasting two and half hours.

4.3.2 Intervention fidelity

An intervention fidelity log was kept. A checklist of topics covered in each module was developed and the programme facilitators indicated topics they delivered after each session (Appendix F). The researcher observed five of the six sessions and also completed the checklist. The programme deviated slightly from the intended sessions with a small amount of content moved from module 2 into module 3. There was a 100% inter-rater agreement between the facilitators' log of content covered and the researcher's log of content covered for the five sessions the researcher observed (Appendix G).

Participants' attendance on the programme was monitored with a sign in sheet. No participant left early on the days they attended. As identified, one participant's data was not included in the study, as they had not attended one of the days of the programme, missing two of the six modules covered in the programme.

Active discussion was encouraged throughout the programme to support the sharing of experiences and knowledge to support learning. This will influence the integrity of consistency across AEWA programmes, as the discussions will vary across programmes based on the experience and characters of the participants.

4.3.3 Data collection procedure

The Time 1(T_1) measures were sent by post to the participants in both the experimental and wait-list control group a week before the start of the summer programme. Prior to sending the measures, the researcher contacted all the participants by telephone to make them aware the measure would be arriving in the post and explaining they could make contact if any questions or concerns arose when completing them. Participants in the experimental group were asked to bring the completed T_1 measure to the first session. The participants in the control group were asked to return the completed T_1 measure within a week of the start of the summer AEWA programme.

The experimental group completed the T_2 measures at the end of the last session of the programme. The control group were posted the T_2 measures at a corresponding time and were asked to complete and return them within a week.

4.3.4 Measurement Methods

4.3.4.1 Rationale for specifically constructing a measure

As identified in the systematic review of research section 2.6, very few studies have evaluated parent-focused interventions aimed at developing parents' knowledge and confidence to enable them to promote the emotional well-being of children with autism, and to support them in the potential challenge of adolescence. As a result, there is a lack of relevant parental measures identified for use in this research.

A range of different measures have been used with parents when evaluating more generic interventions aimed at parents of children with autism. Measures used have focused on child outcomes such as Vineland Adaptive Behaviour Scales II (VABS-II; Sparrow, Cicchetti & Balla, 2005) and the Autism Diagnostic Interview, Revised (ADI-R; Rutter, Le Couteur & Lord, 2003). Other measures have focused on parent outcomes, such as parental stress, for example the Parental Stress Inventory (PSI; Abidin, 2012) and the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg & Crnic, 1983).

As the decision to focus on outcomes relating to parents' perceived knowledge and confidence had been taken, instruments focusing on these outcomes were explored. In a review by Črnčec, Barnett, and Matthey (2010), thirty-six instruments assessing parenting knowledge and confidence were identified. The instruments focused on different dimensions of parental knowledge and confidence but no instrument focused specifically on outcomes of interest in this study.

As a consequence of the difficulties identifying a relevant instrument for this study, the researcher concluded it was appropriate to construct a bespoke instrument to measure constructs of parents' perceived knowledge and confidence in dimensions of promoting the emotional well-being of their child with autism and supporting them through the potential challenges of adolescence.

Previous studies have developed bespoke measures to capture the outcomes targeted in interventions. Dimensions of parental knowledge and confidence are often measured in instruments, specifically related to the content of the programmes they seek to evaluate. For example, the Autism: Parent Questionnaire (APQ; Anderson, Birkin, Seymour & Moore, 2006) was developed to evaluate the National Autistic Society Early Bird Programme and Sofronoff and Farbotko, (2002) developed an instrument to measure the outcomes of an intervention that focused on knowledge and confidence in behaviour management.

4.3.4.2 Developing an instrument

Rating scales are widely used in research and can provide an engaging approach to capturing peoples' attitudes (Robson, 2011; Oppenheim, 2005), so a bespoke measurement instrument was developed for this study, built around Likert scales in a self-report survey. The survey developed was designed to assess the anticipated outcomes of the AEWA programme, which is the independent variable. The measurement instrument developed for this study primarily generated ordinal data, with some nominal data to support the interpretation.

The items included in the survey sought to explore the dependent variables identified in Table 4.4.

Perceived knowledge	• To promote the emotional well-being of their child with autism • To support their child with autism through the potential challenges of adolescence
Perceived confidence	• To promote the emotional well-being of their child with autism • To support their child with autism through the potential challenges of adolescence

Table 4. 4 Dependent variable constructs

The eight steps identified by Cohen et al, (2011) were used to guide the development of the survey. An overview of the steps and how they were applied is shown in Table 4.5. As discussed in Oppenheim (2005) technical concerns related to wording and answer coding were also considered throughout the development of the survey.

Identify the purpose	The review of relevant literature, the aims of the current study and the rationale for it are discussed in Chapter 2. The purpose of the survey was to capture data to address the research questions generated.
Decide the population and sample	The target population has been guided by who the AEWA intervention programme is targeted. Sample decisions have been discussed.
Generate the constructs to be addressed to ensure the required data for the purpose of the research is collected	Constructs were generated from the topics covered in the AEWA programme to support content validity. o Knowledge - Promoting emotional well-being o Confidence - Promoting emotional well-being o Knowledge - Supporting in adolescence o Confidence - Supporting in adolescence
Decide the measurement/questions to be included	Questions • Question items linked to the identified dependent variables constructs being investigated • Demographic questions included to support the interpretation of the data captured Measurement

	• Ordinal data collected on question items related to the dependent variables • Categorical and ordinal data collected in demographic questions
Write the survey items	Survey items were developed directly relating to the content of the AEWA programme.
Check there are several items to address constructs identified	The items relating to each construct were identified (see Appendix H).
Pilot survey and refine as appropriate	The survey was piloted with five parents who had children with autism. They were asked to comment on the time taken to complete the survey, ease of completion and areas for development (Appendix I). No significant amendments were made to the survey as a result of the pilot.
Administer the survey	The survey was administered in spring 2017 to self-selecting participants in the experimental and control group.

Table 4. 5 Eight steps taken to develop the bespoke self–report survey adapted from Cohen, Manion & Morrison (2011) p.37

The survey developed can be seen in Appendix E. As personal details were collected from the participants pre-intervention (T_1), the personal data questions included in the survey were adapted for use post-intervention (T_2) focusing on capturing any information about interventions received concurrently with the AEWA programme (Appendix J).

4.3.4.3 Reliability and validity of the instrument

It is acknowledged that the survey developed had not been used in any other studies to support an evaluation of its reliability and validity. However, actions were taken by the researcher to enhance the reliability and the validity of the instrument.

To support the content validity of the measure the content of the programme was used to directly inform the items used in the measure. To check the reliability of the survey, groups of items were included to measure each construct (Appendix H). Cronbach's Alphas were undertaken after data was collected to explore the reliability of the item groupings for each construct, assessing the internal consistency of the items scores to identify how closely items they were related. The Cronbach Alpha values can be seen in Table 4.6.

There is debate about the acceptable levels of Cronbach Alpha Nunnally (1967) suggests 0.9 while this has been argued to be too high (Boyle, 1991). A widely acceptable level is a score is 0.7 or above (George & Mallery, 2003). As can be seen in Table 4.6, the scores achieved fall slightly below for two of the constructs T_1. The small number of items used for these constructs may be responsible for artificially deflating the figure. As the scores are very close to 0.70 and this is the first time the instrument has been used, the reliability of the scale has been deemed acceptable for this study but it is identified as an area for future consideration.

Construct measured	Number of items	Cronbach Alpha scores	
		T1 measure	T2 measure
Perceived knowledge to promote the emotional well-being of their child with autism	16	0.859	0.946
Perceived confidence to promote the emotional well-being of their child with autism	7	0.817	0.917
Perceived knowledge to support their child with autism through the potential challenges of adolescence	6	0.689	0.949
Perceived confidence to support their child with autism through the potential challenges of adolescence	5	0.672	0.855

Table 4. 6 Internal consistency of items measuring constructs

4.4 Validity of Quantitative Design

When conducting research, threats to reliability and validity cannot be entirely diminished, however, potential threats can be minimised by considering them and taking appropriate actions to minimise them throughout the research. Validity in quantitative research refers to the accuracy of the findings. It is concerned with whether there is "*a real, direct link between two things*" (Robson, 2011; p85). The different types of validity impacting on a study will be considered in the following subsections.

4.4.1 Internal validity

Internal validity refers to a study's ability to attribute outcomes found on the dependent variable to a causal relationship with the independent variable. To achieve internal validity in a study, extraneous variables need to be controlled.

In this study, establishing internal validity enabled any changes in parents' perceived knowledge and confidence in supporting the emotional well-being of their child with autism and supporting them through adolescence, to be attributed to the independent variable, the AEWA programme.

Twelve threats to the internal validity of a study have been identified by Cook and Campbell (1979), building on the work of Campbell and Stanley (1963). Not all threats to internal validity identified are present in all study designs. Table 4.7 provides a summary of the threats to the internal validity of this study and how they have been addressed.

Possible threat to internal validity and meaning for this study	Actions taken to minimise threats
History - External events potentially impact upon participants' results unrelated to the study. Children and young people with autism form a heterogeneous group. Each participant within this study will have a range of historical and concurrent experiences with their child with autism. The researcher is unable to control things in the participant environment that may be responsible for any changes that occur between the reported knowledge base and perceived confidence in the T1 and T2 measures.	At T1 participants were asked about factors related to themselves and their child with autism, which could potentially impact on their individual outcomes. At T2 participants were asked to identify if they had accessed other interventions and services during the intervention period. This information will be considered in the interpretation of the results. Illustrative case studies from participants about their historical and current experiences can be triangulated with the quantitative results to support the interpretation.
Testing **-** Experience completing a measure can influence subsequent results when using the measure repeatedly. Repeatedly completing a measure can impact upon how participants respond to the questions.	Completing the measures on only two occasions will minimise the test effect.

Instrumentation - Non-equivalent measures, analysis and interpretation is used pre- and post-test. Changes in the way the T_1 and T_2 measures are interpreted and scored can account for change observed in the pre- and post-measures.	The T_1 measure was piloted with five individuals prior to use. Issues such as ease of understanding and items included were considered. Cronbach's Alpha was used to test the internal consistency of responses pre- and post-test. The same measure was used at T_1 and T_2. A clear and objective scoring criterion were established when the measure was developed, to minimise the subjective interpretation and bias of the researcher.
Regression - Regression to the mean in pre- and post-test scores can lead to the inaccurate attribution of the cause of changes observed. Participants who scored unusually at T_1 are likely to show less unusual scores at T_2.	The study used non-parametric tests in the analysis of the data, so normal distribution assumptions did not need to be met and outlier scores could be included.
Mortality - Participants withdrawing from the study. Participants who do not feel they are benefiting from the programme may not complete the full intervention AEWA programme or complete the measures at T_2.	The researcher was aware they were unable to gain a sufficient sample size to account for attrition. Interpretation of the results of the study will consider the small sample.

Maturation - Changes in participants, such as growth and development, unrelated to the study, impact on the outcome. The participants in the study may experience changes, which will affect the outcomes being measured.	As the programme is run over three weeks it is a limited time for maturation effects. Parents attend the AEWA programme due to a perceived need for knowledge. It was unlikely this perceived need would be met, within the short time span alone.
Selection - Group differences prior to the start of the study will impact on different outcomes for the two groups. Non-probable sampling strategy used in the study increases the likelihood the participants in the experimental and control group will be different in their T_1 measures. This difference could impact on any outcomes at T_2.	Pre-analysis checks to compare group equivalence and check for homogeneity using the Mann-Whitney U test were undertaken for the experimental and wait-control group.
Diffusion of treatment - One group learns the information from the intervention inadvertently form another group. The control group learns about information from the intervention AEWA programme from the experimental group, which is reflected in the outcomes of the T_2 measures.	Recruitment for the AEWA programme was from a large rural county. Part of the allocation to a programme was based on the geographical area they lived to ensure individuals could access their closest programme. Participants from the experimental group were from one part of the county and participants from the control group were from another part. This

	minimised the potential for contact between participants and diffusion of treatment.
Compensatory rivalry: Participants not receiving the intervention will receive additional support due to their group status to compensate for not receiving the intervention.	The 'wait list' control group was offered the opportunity to receive the intervention, prior to their involvement participation in the study. They were aware they would receive the same input as the experimental group, although it is acknowledged it would not be at the same time.

Table 4. 7: Threats to internal validity and a summary of actions taken to minimise them

4.4.2 External Validity

External validity refers to generalisability of a study's finding to another setting or across client groups. LeCompte and Goetz (1982) identified four threats to generalisability, which are recognised as potentially impacting on this study. The first threat to external validity is selection, referring to the findings of a study only being specific to the participants included in the study. Second is setting, which is concerned with how replicable the findings are across contexts. The third threat to generalisability is history, which recognises the influence participants' history can have on the findings, which has consequences for replicating them. The final threat is the construct effect, concerned with how transferable the findings are beyond the specific group in the study. The impact of these threats will be considered when exploring the limitation of the study (section 8.4) and the implications for practice (section 8.6).

4.5 Approach to statistical analysis

To support all the statistical analysis in this study, where possible the researcher used IBM SPSS Statistics 24 software.

4.5.1 Parametric versus non-parametric approaches to analysis

Ordinal data was primarily generated through the surveys. Ordinal data has clearly defined levels but even when represented by integers the interval between each level is not certain. There has been debate about the use of parametric and non-parametric statistics when using ordinal data (Norman, 2010; Kurzon, Urbanchek & Mccabe, 1996).

The data collected in this study is ordinal, it is from a small sample and the data did not meet normality assumptions. Therefore, as the data violate the required assumptions for parametric analysis identified by Kurzon et al. (1996), non-parametric approaches to analysis have been chosen in this study.

4.5.2 Computing variables

To compute the scores for each of the four constructs measured in the survey for each participant, the score of the items relating to each construct were added together and then divided by the number of items (Pallant, 2013). As scores could not be computed in SPSS, where there was missing data the researcher was required to manage the missing data.

4.5.3 Treatment of missing data

The data sets for two participants in this study were not complete; one participant failed to score one item, while another failed to score two items. To enable variable to be computed using a number of items, missing data can be managed by excluding participants' data (Pallant, 2013; Oppenheim, 2005) or by replacing missing variable using the mean (Brace, Kemp Snelgar, 2012).

It was not deemed appropriate to exclude participants' data in the analysis due to the already very small sample and the possible distortion of replacing the missing data was deemed to be very small due to the relatively small number of items missed. Therefore, participants' missing data was replaced. As the data was ordinal, the median value of the items for the construct was used rather than the mean.

4.5.4 Mann-Whitney U Test

The Mann-Whitney U test was used to check for group equivalence between the experimental and control group in the T_1 and T_2 measures. The Mann-Whitney U Test is a non-parametric equivalent to a t-test, comparing two independent samples. It can use ordinal data, comparing the scores identified on a continuous measure of two independent groups.

4.5.5 Wilcoxon Signed Rank Test

The Wilcoxon Signed Rank test was used to analyse the intervention effect. The Wilcoxon Signed Rank test compares the scores of a group taken under two conditions or at two time points to identify if there is a significant difference between the repeated measures. Like the Mann-Whitney U, it converts the test

scores to rank scores across T_1 and T_2, comparing how many times the ranked scores in one condition are higher than in the other.

4.5.6 Statistical significance

The null hypothesis is based on the assumption that there will be no real difference between the conditions. To assess the null hypotheses, the statistical significance of any difference will be tested. For null hypotheses to be rejected in this study, the statistical significance will be set at 5% (expressed as $p < 0.05$).

4.5.7 Type I and Type II errors

When using statistical significance level for null hypotheses testing as done in this study, there are two types of errors to note that can occur. A Type I error occurs when the null hypothesis is rejected in error when it is actually true. A Type II error could occur in this study if the null hypothesis is accepted and we assume there is no difference when it is actually false and a difference exists.

In this study, by accepting the 5% statistical significance level to reject the null hypotheses, we are accepting that there is a less than 5% chance that a Type I error could occur. It could be argued that a 5% chance of rejecting the null hypotheses in error is too high and a lower threshold of statistical significance should be used. However, it is important to consider there is an inverse relationship between a Type I error and a Type II error so lowering the possibility of making a Type I error, increases the probability of making a Type II error (Kurzon, 1996).

Statistical significance is influenced by the sample size. It is easier to achieve a statistically significant result, as the sample increases with the same actual difference. As the size of the sample in this study is small, it is acknowledged that there is a risk of making a Type II error, accepting the null hypotheses when there is a difference, which has not been identified due to the sensitivity of the test.

4.5.8 Effect size

In addition to the statistical significance, the American Psychological Association, (2010) have called for the reporting of effect size to help determine

the magnitude or importance of an effect. As the computed statistical significance of a test is influenced by the sample size, it is important to know what is responsible for the significant result, which can be identified by calculating the effect size (Kline, 2004). The effect size provides an indication of the degree to which two variables are associated with each other, which is also known as the 'strength of association' (Robson, 2011).

There is a range of different calculations that can be used to generate an effect size and it has been suggested there is no one single optimal method (Wilcox & Serang, 2016). One widely accepted effect size calculation is Cohen's d (1988), which compares the difference between means, relative to the standard deviations of the scores. This test requires the same underpinning assumptions of normal distribution of the samples and a common variance. As these assumptions have not been met in this study, it was not deemed appropriate for use.

Using Pallant's (2013) suggestion, approximate correlation effect sizes were manually calculated in this study (Appendix K). Z-Scores identified in the Mann-Whitney and Wilcoxon Signed Ranks tests are used in the following calculation:

r = z / square root of N

Mann-Whitney U Test	N = total number of cases.
Wilcoxon Signed Rank Test	N = the number of observations over the two time points.

(Pallant, 2013, p. 238)

For interpretation of the effect size, Cohen's (1988) criteria is used for interpreting correlation effect size where 0.1 will be considered a small effect, 0.3 a medium effect and 0.5 a large effect. The calculated effect size will indicate only whether a shift has occurred and should not be viewed as an absolute value, as the data gathered in this study is ordinal, so has no intrinsic value. To provide a richer picture, a brief descriptive commentary will be provided about the direction of the shift and extent to which a shift is observed.

4.6 Summary

This section has given an overview of the qualitative design detailing the approach to data collection and analysis, while also considered issues of reliability and validity affecting this study.

The following section will now go on to explore the findings from the data gathered using the quantitative design discussed.

Chapter 5 - QUANTITATIVE RESULTS

5.1 Introduction to the chapter

This chapter summarises the results of the statistical analysis undertaken with the data gathered on parents' perceived knowledge and confidence. Hypotheses related to each research question were tested in turn to determine whether there was a statistically significant change on the dependent variables that could be attributed to the AEWA programme. Group equivalence was tested initially, followed by an analysis of the intervention effect. For a positive change to be attributed to the AEWA programme, a statistically significant change would be observed on the dependent variables captured on the bespoke measures, between T_1 and T_2 for participants in the experimental condition; such change would not be observed in the wait control condition.

5.2 Research question one

Does the Autism, Emotional Well-being and the Adolescence programme increase parents' perceived knowledge and skills related to emotional well-being to support their child with autism through the potential challenges of adolescence?

5.2.1 Hypothesis

Null Hypothesis:	There will be no significant difference in parents' self-reported perceived knowledge to supporting the emotional well-being of their child following their participation in the AEWA programme.
Alternative Hypothesis:	Participation in the AEWA programme will lead to a change in parents' self-reported perceived knowledge related to supporting the emotional well-being of their child. This change will not be observed in the control group.

5.2.2 Analysis

The descriptive statistics for pre- and post-intervention scores of parents' self reported perceived knowledge of emotional well-being and strategies to promote it are summarised in Table 5.1.

	T_1 - Pre-intervention			T_2 - Post-intervention		
	Median	Range	Standard Deviation	Median	Range	Standard Deviation
Experimental Group *n* = 9	3.625	2.94-3.75	0.32	4.375	3.94-4.88	0.31
Control Group *n* = 10	3.594	2.50-3.81	0.42	3.469	2.88-4.88	0.35

Table 5. 1: Pre- and post-intervention scores of parents' self reported perceived knowledge of emotional well-being and strategies to promote it.

Group equivalence

Analysis of the T1 pre-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

> There was no significant difference between the scores of the experimental group (*Md* = 3.63, *n* = 9) and the control group (*Md* = 3.59, *n* =10) at T1 pre-intervention, *U* = 37.00, *p* = 0.510 two tailed, *Z* = 0.66, *r* = 0.15.

Analysis of the T2 post-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

> There was a significant difference between the experimental group (*Md* = 4.375, *n* = 9) and the control group (*Md* = 3.469, *n* =10) scores at T2 post-intervention, *U* = 0.00, *p* = 0.000 two tailed, *Z* = 3.68, with a large effect size (*r* = 0.844).

Intervention effect

Analysis of the T1 and T2 scores of parents' self-reported perceived level of knowledge of emotional well-being and strategies to promote it, was undertaken using the Wilcoxon Signed-Rank test.

> Analysis of the experimental group ratings scores, indicated a significant difference between T1 scores with T2 scores *Z* = -2.68, *n* = 18 (2x9), *p* = 0.007 two tailed, with a large effect size (*r* = 0.63). Comparison of the corresponding values at T1 and T2, indicated 100% of participants in the experimental group reported an increase in their perceived level of understanding of emotional well-being and strategies to support it following their participation in the AEWA programme.
> In the control group, no significant difference was identified when comparing in the ratings of T1 scores with T2 scores *Z* = 0.78, *n* = 20 (2x10), *p* = 0.436 two tailed, with a small effect size (*r* = 0.17). Corresponding values representing participants perceived level of

knowledge of emotional well-being and strategies to support their child with autism were compared at T_1 and T_2. Results indicated 30% of participants in the control group reported a decrease in their perceived knowledge at T_2, 20% were unchanged and 50% reported an increase. Overall 50% of participants reported the same level or lower level of perceived knowledge of emotional well-being and strategies to support.

5.2.3 Summary

There was a significant difference pre- and post-intervention in parents' self-reported perceived level of understanding of emotional well-being and strategies to promote it in the experimental group. This difference was not observed in the wait-list control group.

5.2.4 Hypothesis

Null Hypothesis: There will be no significant change in parents' self-reported perceived knowledge of the potential challenges in adolescence for their child with autism and strategies to support them, following their participation in the AEWA programme.

Alternative Hypothesis: Participation in the AEWA programme will lead to an change in parents' self-reported perceived knowledge of the potential challenges in adolescence for their child with autism and strategies to support them. This change will not be observed in the control group.

5.2.5 Analysis

The descriptive statistics for pre- and post-intervention scores of parents' self reported knowledge of potential challenges in adolescence for their child with autism and strategies to support them are shown in Table 5.2.

	T_1 - Pre-intervention			T_2 - Post-intervention		
	Median	Range	Standard Deviation	Median	Range	Standard Deviation
Experimental Group *n* = 9	2.83	2.33-3.50	0.45	4.33	3.67-4.83	0.32
Control Group *n* = 10	2.92	2.00-3.50	0.55	2.67	2.00-3.50	0.53

Table 5. 2: Pre- and post-intervention scores of parents' self reported knowledge of potential challenges for their child with autism in adolescence and strategies to support them.

Group equivalence

Analysis of the T1 pre-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

> There was no significant difference between the score of the experimental group (*Md* = 2.83, *n* = 9) and the control group (*Md* = 2.92, *n* =10) at T1 pre-intervention, *U* = 42.00, *p*= 0.806 two tailed, *Z* = -0. 25, *r* = 0. 06.

Analysis of the T2 post-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

> There was a significant difference between the scores of the experimental group (*Md* = 4.33, *n* = 9) and the control group (*Md* = 2.67, *n* =10) at T2 post-intervention, *U* = 0.00, *p* = 0.000 two tailed, *Z* = 3.68, with a large effect size (*r* = 0.84).

Intervention effect

Analysis of the within group T1 and T2 scores of parents' self-reported perceived knowledge of potential challenges in adolescence and how to support them, was undertaken using the Wilcoxon Signed-Rank test.

> Analysis of the experimental group ratings scores, indicated a significant difference between T1 scores with T2 scores *Z* = -2.67, *n* = 18 (2x9), *p* = 0.008 two tailed, with a large effect size (*r* =0. 0.63). Comparison of the corresponding values at T1 and T2, indicated following the participation in the AEWA programme, 100% of participants in the experimental group reported an increase in their perceived level of knowledge of the potential challenges in adolescence for their child with autism and how they can support them.

> In the control group, no significant difference was identified when comparing the ratings of T1 scores with T2 scores *Z* = 0.916, *n* = 20 (2x10), *p* = 0. 360 two tailed, with a small effect size (*r* = 0.205).

Corresponding values representing participants perceived level of understanding of potential challenges in adolescence, for their child with autism and how they can support them through that phase of development compared at T_1 and T_2. 50% of participants in the control group reported a decrease at T_2, 20% were unchanged and 30% reported an increase. Overall, 70% of participants in the control group reported the same level or lower level of perceived knowledge of the potential challenges in adolescence for their child with autism and strategies to support.

5.2.6 Summary

There was a significant difference pre- and post-intervention in parents' self-reported perceived level of understanding of potential challenges in adolescence and how to support in the experimental group. This difference was not observed in the wait-list control group.

5.3 Research question two

Does the Autism, Emotional Well-being and the Adolescence programme increase parents' perceived confidence in promoting the emotional well-being of their child with autism and support them through the potential challenges in adolescence that may impact upon their well-being?

5.3.1 Hypothesis

Null Hypothesis:	No significant difference will be found in parents' self-reported perceived confidence in their ability to promote the emotional well-being of their child with autism following their participation in the AEWA programme.
Alternative Hypothesis:	Participation in the AEWA programme will lead to an change in parents' self-reported confidence in their ability to promote the emotional well-being of their child with autism.

5.3.2 Analysis

The descriptive statistics for the pre- and post-intervention scores of parents' self reported confidence in promoting the emotional well-being of their child with autism are shown in Table 5.3.

	T_1 - Pre-intervention			T_2 - Post-intervention		
	Median	Range	Standard Deviation	Median	Range	Standard Deviation
Experimental Group *n* = 9	3.25	1.88-4.00	0.67	4.00	3.25-5.00	0.57
Control Group *n* = 10	3.50	2.38-3.88	0.42	3.38	2.50-4.00	0.42

Table 5. 3: Pre- and post-intervention scores of parents' self reported confidence in promoting the emotional well-being of their child with autism.

Group equivalence

Analysis of the T1 pre-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

> There was no significant difference between the scores of the experimental group (*Md* = 3.25, *n* = 9) and the control group (*Md* = 3.50, *n* = 10) at T1 pre-intervention, *U* = 41.50, *p* = 0.774 two tailed, *Z* = -0. 0.29 *r* = 0. 07.

Analysis of the T2 post-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

> There was a significant difference between the experimental group (*Md* = 4.00, *n* = 9) and the control group (*Md* = 3.38, *n* = 10) scores at T2 post-intervention, *U* = 9.50, *p* = 0.002 two tailed, *Z* = 2.91, with a large effect size (*r* = 0.67).

Intervention effect

Analysis of the T1 and T2 scores of parents' self-reported perceived level of confidence in promoting the emotional well-being of their child with autism was undertaken using the Wilcoxon Signed-Rank test.

> Analysis of the experimental group ratings scores, indicated a significant difference between T1 scores with T2 scores *Z* = -2.54, *n* = 18 (2x9), *p* = 0.011 two tailed, with a large effect size (*r* = 0.60). Comparison of the corresponding values at T1 and T2, indicated following the participation in the AEWA programme, 89% of participants in the experimental group reported an increase in their perceived level of confidence in promoting the emotional well-being of their child with autism following their participation in the AEWA programme, while the confidence of 11% (representing one participant) remained unchanged.
>
> In the control group, no significant difference was identified when comparing the ratings of T1 scores with T2 scores *Z* = 0.955, *n* = 20

(2x10), p = 0.339 two tailed, with a small effect size (r = 0.214). Corresponding values representing participants perceived level of confidence in promoting the emotional well-being of their child with autism were compared at T_1 and T_2. It indicated 60% of participants in the control group reported a decrease at T_2, 10% were unchanged and 30% reported an increase. Overall 70% of participants reported the same level or a lower level of perceived confidence in promoting the emotional well-being of their child with autism at T_2.

5.3.3 Summary

There was a significant difference pre- and post-intervention in parents' self-reported perceived level of confidence in promoting the emotional well-being of their child with autism in the experimental group. This difference was not observed in the wait-list control group.

5.3.4 Hypothesis

Null Hypothesis:	Participation in the AEWA programme will not lead to a significant difference in parents' self-reported perceived confidence in their ability to support their child with autism through the potential challenge of adolescence that may impact upon emotional well-being.
Alternative Hypothesis:	Participation in the AEWA programme will lead to a change in parents' self-reported confidence in their ability to support their child with autism through the potential challenges of adolescence that may impact upon emotional well-being.

5.3.5 Analysis

The descriptive statistics for the pre- and post-intervention scores of parents' self reported confidence in supporting their child with autism through the potential challenges in adolescence that may impact upon emotional well-being are shown in Table 5.4.

	T1 - Pre-intervention			T2 - Post-intervention		
	Median	Range	Standard Deviation	Median	Range	Standard Deviation
Experimental Group *n* = 9	3.20	2.80-4.40	0.48	4.60	3.60-5.00	0.47
Control Group *n* = 10	3.30	2.20-4.00	0.55	3.00	2.40-4.00	0.52

Table 5. 4: Pre- and post-intervention scores of parents' self reported confidence in supporting their child with autism through the potential challenges in adolescence that may impact upon emotional well-being.

Group equivalence

Analysis of the T_1 pre-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

- There was no significant difference between the experimental group (*Md* = 3.20, *n* = 9) and the control group (*Md* = 3.30, *n* = 10) scores at T_1 pre-intervention, *U* = 40.00, *p* = 0.720 two tailed, *Z* = 0.41, *r* = 0.10.

Analysis of the T_2 post-intervention scores for the two independent samples was undertaken using the Mann-Whitney test.

- There was a significant difference between the experimental group (Md = 4.6, n= 9) and the control group (*Md* = 3, *n* = 10) scores at T_2 post-intervention, *U* = 4.50, *p* = 0.000 two tailed, *Z* = 3.33, with a large effect size (*r* = 0.76).

Intervention effect

Analysis of the within group T_1 and T_2 scores of parents' self-reported perceived confidence in supporting their child with autism through the potential challenges in adolescence, was undertaken using the Wilcoxon Signed-Rank test.

- Analysis of the experimental group ratings scores, indicated a significant difference between T_1 scores with T_2 scores *Z* = 2.50, *n* = 18 (2x9), *p* = 0.008 two tailed, with a large effect size (*r* = 0.59). Comparison of the corresponding values at T_1 and T_2, indicated following the participation in the AEWA programme, 89% of participants in the experimental group reported an increase in their perceived level of confidence in their ability to support their child with autism through the potential challenges of adolescence, while the confidence of 11% (representing one participant) decreased.

- In the control group, no significant difference was identified when comparing the ratings of T_1 scores with T_2 scores *Z* = -1.10, *n* = 20

(2x10), $p = 0.270$, two tailed with a small effect size ($r = 0.25$). Corresponding values representing participants perceived level of confidence in their ability to support their child with autism through the potential challenges of adolescence were compared at T_1 and T_2. It indicated 40% of participants in the control group reported a decrease at T_2, 30% were unchanged and 30% reported an increase. Overall 70% of participants reported the same level or a lower level of perceived confidence in their ability to support their child with autism through the potential challenges of adolescence.

5.3.6 Summary

There was a significant difference pre- and post intervention in parents' self-reported perceived level of confidence in supporting their child with autism through the potential challenges in adolescence, in the experimental group. This difference was not observed in the wait-list control group.

Chapter 6 - QUALITATIVE DESIGN

6.1 Introduction to the chapter

From a pragmatic stance, a qualitative design was chosen to complement the quantitative methods previously discussed, to help best answer the research questions in this study about the lived experiences of the participants. Through gathering context-rich data using a qualitative approach it enabled the exploration of participants' reflections on their experiences of attending the Autism Emotional Well-being and Adolescence (AEWA) programme and subsequent experiences as a result of attending the programme.

This section provides an overview of the approach to qualitative data collection and analysis. It then goes on to identify the criteria used to ensure the quality of the qualitative design and discuss measures taken within this study to ensure it. As recommended by Guba and Lincoln (1989), criteria aligned to a constructivist position were used in the qualitative design different to that used in the quantitative design.

6.2 Participants

6.2.1 Selection of participants

At the point of recruitment for the quasi-experimental study, potential participants for the experimental group were briefed on the intended data gathering to support both the quantitative and qualitative design used in this study. At the end of the AEWA programme, participants in the experimental group were invited to participate in interviews. Seven parents volunteered and gave consent to be interviewed, however, one was unable to due to personal circumstances. A semi-structured interview was undertaken with the six participants in the self-selecting sample. This is the minimum number of interviews recommended by Braun and Clarke (2013) when seeking to identify a pattern of meaning rather than ideographic meaning.

6.2.2 Description of participants from which qualitative data was collected

All participants interviewed had attended the AEWA programme. Specific details about their individual circumstances were gathered from their completed questionnaire used in the quantitative design and from what was explicitly said in the semi-structured interviews.

Participant 1 – A father to a ten-year-old son. His son received a diagnosis of High Functioning Autism when he was eight-years-old and had recently had his diagnosis updated to include Pathological Demand Avoidant features. He identified he worried a lot about his son's emotional well-being, particularly his anxiety and the associated behaviours. He indicated he is not at home all the time and spends periods away, so caring responsibilities fall to his partner at these times. He attended the programme as it was of interest to him and he came with an open mind of what to expect.

Participant 2 – A mother of a ten-year-old son and partner to participant 1 (see participant 1 for details of her son). She identified she was worried about her son's emotional well-being particularly related to his level of anxiety and some aspects of her child's behaviour. She reflected a feeling of isolation and suggested it had been emotionally challenging at times, parenting a child with autism. She had previously attended parenting programmes and attended the AEWA programme as she hoped to access information that was of relevance to her son and strategies that she could use to support her son.

Participant 3 – A mother of a daughter aged ten-years who had a diagnosis of William's Syndrome, which she received when she was three-years-old and a diagnosis of ASD, which she received nine months prior to the start of the AEWA programme. It was identified that when younger, the daughter of the participant had been angry and displayed some challenging behaviours. She attended the AEWA programme in the hope of gaining some relevant information to support her in parenting her daughter but also her older, typically developing son, who had just transitioned into secondary school and was experiencing high levels of anxiety. She also suggested that at times she feels isolated and she had looked

forward to the AEWA programme offering her the opportunity to meet other parents in similar situations.

Participant 4 – A mother who was a single parent to two children. She had a son aged eleven-years-old, who received a diagnosis of Asperger and Attention Deficit Hyperactivity Disorder when he was five-years-old. Participant 4 also had a daughter aged eight years old who she indicated had ASD. She identified her children's behaviour had been challenging and she had concerns about her children's emotional well-being. She indicated that she felt she had little support parenting her children and experienced feelings of isolation. Participant 4 had previously attended parent programmes and she attended the AEWA programme because of the focus on anxiety and adolescence, which she felt was relevant to her children.

Participant 5- A father of a thirteen-year-old son with ASD. His son received the diagnosis when he was ten-years-old, although a diagnosis had been considered when he was six-years-old, however, parents had decided not to go through with the process. He suggested he had not felt supporting his son's needs relating to his autism as challenging, but raised concerns about his son's anxiety and stress levels. Participant 5 had previously attended a parent programme, which he perceived to be useful. He attended the AEWA programme as it deemed it to be relevant to his son and he was keen to connect with other parents of children with autism.

Participant 6 – A mother of a thirteen-year-old son who had a diagnosis of ASD since he was three and a half-years-old. She identified she had found it difficult to secure support for her son which had been stressful and at times she identified that she feels isolated. Participant 6 identified she was worried about her son's emotional well-being and was scared for her son in some of the potential challenges he faced in the future. She had previously attended parent programmes and attended the AEWA programme as she was concerned about her son going through adolescence and wanted to gain information so she felt more prepared and confident in her ability to support her son.

6.3 Procedure

6.3.1 Intervention

All the participants from whom qualitative data was gathered had been part of the experimental group and had recently attended the AEWA programme. An overview of the programme is given in section 3.8.

6.3.2 Approach to information gathering

Information was gathered through semi-structured, face-to-face interviews. To support consistency between the interviews, a interview protocol was developed as a guide to ensure relevant topic areas were considered (Appendix L). Questions predominantly focused on the research questions, but also included questions to build rapport and gain contextual information from which to consider participants' responses.

The semi-structured approach to the interviews was used, allowing for open-ended questions, modification of questions in response to the flow of the interview and for some unplanned questions to be included. This flexibility allowed the researcher to further probe participants' responses, to encourage them to expand, gain clarification and check their understanding of the responses.

All the interviews were audio recorded and transcribed.

6.3.3 Approach to data analysis

Thematic analysis is a term used to describe different methods of systematic analytical procedures for generating themes from qualitative data, through the generation of codes and theme development (Clarke & Braun, 2016). Thematic analysis can be used within any underpinning ontological and epistemological frameworks (Clarke & Braun, 2016; Joffe, 2012), making it compatible with the mixed method approach used in this study. The approach was chosen for analysis of the qualitative data, as it allows for patterns to be identified across data about participants' lived experiences and their views (Clarke & Braun,

2016) which was felt to be more relevant than idiosyncratic experiences for the evaluation of the AEWA programme.

There are different approaches that can be used to undertake thematic analysis (Braun & Clarke, 2006, 2013; Guest, MacQueen & Namey, 2012; Guest; Joffe, 2012). The six-phase thematic analysis approach identified by Braun and Clarke (2006) was chosen as it provides a clear, transparent process to the data analysis. The phases of the process are detailed below:

- Phase 1 – Familiarisation with the data
- Phase 2 – Generating initial codes
- Phase 3 – Searching for themes
- Phase 4 – Reviewing themes
- Phase 5 – Define and naming themes
- Phase 6 – Producing the report

NVivo computer software was used to support the researcher to arrange the qualitative data electronically for analysis. During the initial stages, the data gathered was analysed as a whole body of data and not in relation to each of the research questions. The researcher took this decision as the naturalistic approach taken in the semi-structured interviews meant there was some variance in the questions participants were asked and their responses did not exclusively link to one research question. As part of reviewing the themes in phase 4 of the thematic analysis process, the relevance of each theme was considered in relation to each of the research questions.

Data was analysed at the semantic level, considering only what participants explicitly said. The researcher limited the assumptions they were required to make by not attempting to uncover the latent meanings of what was being said by participants.

The body of data was analysed using an inductive approach. The absence of a theoretical framework allowed initial codes and themes to emerge from the data. An inductive approach is useful in new areas of exploration (Braun & Clarke, 2017) and as previously identified in the systematic review of evidence very limited research exists in the area of promoting the emotional well-being of children and young people with autism through adolescence parent programmes.

During phase one, the researcher familiarised themselves with the data by listening to the audio recording of the interviews and reading through the transcripts of the interviews on two occasions.

During phase two, the researcher worked independently, coding the whole body of data on three separate occasions to avoid 'coding drift,' ensuring that all the data was considered through the new insights and understanding developed through the initial process of data coding. An illustrative example of a part of a coded transcript in NVivo can be seen in Appendix M. Moving onto phase three; the codes were reviewed to identify possible themes. Sub-themes were also identified as part of this process, which highlighted a particular aspect emerging under the central organising themes (Braun and Clarke, 2013). The themes and sub-themes developing from the initial codes can be seen in Appendix N.

In the fourth phase, all candidate themes were then considered reviewing the evidence to support them. Subsequently, some themes were removed where there was not appropriate evidence to support, some were collapsed and some were broken into emerging themes. Thematic maps were then created in response to each of the research questions identifying possible themes and sub-themes. The researcher then reviewed the whole body of data again using the thematic maps taking a deductive approach, to identify any further evidence to support the emerging themes, illustrative examples of data to support the themes and the sub-themes can be seen in Appendix O. Candidate themes were accepted when it was identified there was evidence to support the theme from fifty percent of the participants.

To support the reliability of the themes identified by the researcher, two 'blind' raters independently coded ten percent of extracts of the data in relation to the thematic map produced by the researcher. The level of agreement and disagreement was calculated (Appendix P) and the percentage agreement between the raters and the researcher can be seen in Table 6.1.

	Percentage of agreement with 'blind' independent rater 1	Percentage of agreement with 'blind' independent rater 2
Participants' reflections of their experience of attending the AEWA programme data codes	86%	88%
Participants' subsequent experiences as a result of attending the AEWA programme data codes	79%	82%

Table 6. 1: Agreement between the researcher and '*blind rater'* in the coding decisions of extracts of data

An agreement of 75% has been suggested as an acceptable level to support the robustness of the themes identified (Joffe, 2012). As this level was reached, the researcher reflected positively on the robustness of the themes identified. The 'blind' raters and researcher discussed their coding of each extract, exploring reasons for any differences. From the discussions, a slight amendment was made to the thematic map.

The results of the thematic analysis are discussed in Chapter 7, which includes the thematic maps and a report on the themes identified in response to the research questions.

6.4 Ensuring the quality of the quantitative design

Lincoln and Guba (1985) suggest that credibility, transferability, dependability and conformability should be considered when evaluating the quality of qualitative research. Mertens (2015) suggests these criteria parallel that considered when accessing the quality of quantitative research with credibility equating to internal validity, transferability with external validity, dependability with reliability and conformability with objectivity.

6.4.1 Credibility

In qualitative research, Maxwell (2017) suggests there are threats to the validity in the description, meaning/interpretation, and explanation. To ensure the data body was complete and accurate from which a valid description was generated, all interviews were audio recorded and transcribed verbatim. To support the validity of the interpretation of the data, Braun & Clarke's (2006) thematic analysis was used. The structured analytical procedure allowed theory to emerge from the data rather than a theory being imposed. A reflective log of the choices made was kept through the data analysis. To support the validity of the theory generated and avoid the risk of not considering alternative explanations, the researcher sought peer support through the analytical process and completed inter-rater checking, discussing discrepancies in interpretations which included considering alternative explanations.

The researcher embedded a number of strategies in the study to reduce the risk/effect of bias and enhance the rigour of the qualitative design as highlighted by Robson (2011). These are detailed in Table 6.2.

Prolonged and persistent engagement	The researcher had limited contact with participants. The researcher was in direct contact with participants during the recruitment of the sample, when disseminating the measures and for one interview. This ensured sufficient closeness to gain appropriate data, while reducing the risk of bias that is associated with prolonged and persistent engagement.
Triangulation	The qualitative and quantitative findings were triangulated to consider the convergence of the data findings and explore alternative explanations. Another person also looked at samples of the data to identify discrepancies and explore alternative explanations.
Peer debriefing and support	Throughout the data gathering and analysis, the researcher closely liaised with a peer who posed questions to the researcher about their decisions in their analysis and explored possible considerations.
Member checking	Member checking was undertaken with participants in the interviews. The researcher summarised and reflected back their understanding of participant responses and, where needed, asked questions to seek further clarification. This checking ensured the researcher's construction of the data reflected the intended meaning of the participants to support the accuracy of their interpretation.
Negative case analysis	A negative case analysis to identify data that disconfirmed the theory developed in the thematic analysis was not undertaken within this study. However, as part of the analysis, where there was a lack of evidence to support arising themes, they were removed, adapting the emerging theory. The analysis involved in the quantitative design identified cases that supported the null hypothesis, negative cases of the theory identified in the hypotheses.
Audit trail	A record of the researcher's decisions were captured in a research log, which formed a record of how the researcher's constructions developed as they went through the analysis process. This supported the researcher to be explicit in the decisions they took and help the identification of biases in their analysis.

Table 6. 2: Strategies used by the researcher to support the rigour of the study

6.4.2 Transferability

In qualitative research, the criterion in quantitative research for studies to include a representative sample to support the generalisation of findings is not applicable. Lincoln and Guba (1985) suggest it is the responsibility of the reader to identify the similarities and differences in the research situation to their own when considering the transferability of the findings. To enable this to happen, a description of the participants involved in the qualitative design has been provided in section 6.2.2.

It has been suggested the use of multiple cases and consideration of how they relate can support decisions about generalisability (Yin, 2009). In the qualitative design, data was gathered from six participants, who formed an appropriate sample having received intervention. As identified in section 6.3.3 a recognised structured approach to thematic analysis was used to identify patterns within the data.

6.4.3 Dependability

Dependability in qualitative research is concerned with ensuring the quality and appropriateness of the methods used in the inquiry process (Mertens, 2015). As recommended by Easton, McComish and Greenberg (2000), precautions were taken against problems in data collection and transcription. Data was gathered in a quiet environment in which distractions were minimised using two audio recording devices. Transcriptions of the data were then checked by reading them and listening to the audio recordings simultaneously.

6.4.4 Confirmability

Confirmability is about the data and conclusions drawn by the researcher as being supported by evidence and not made up by the researcher (Mertens, 2015). In this study, evidence to support the conclusions drawn by the researcher were collated as part of the analysis and reviewed with a peer. Illustrative examples of the evidence to support the researchers conclusions are presented in the results section (Chapter 7). Two 'blind' inter-raters also

reviewed samples of the data collected in relation to the researcher's conclusions.

Chapter 7 - QUALITATIVE RESULTS

7.1 Introduction to the chapter

The following section describes the themes and sub-themes that arose from the thematic analysis completed using Braun and Clarke's (2006) six-step process. A thematic map in response to each research question is provided identifying the higher order themes and their sub-themes in response to each research question. Examples of data extracts from the participants are then identified to illustrate themes at each level.

7.2 Thematic results: Participants' reflections of their experiences of attending the Autism, Emotional Well-being and Adolescence programme.

The themes and sub-themes identified through the thematic analysis, identified as relevant to participants' reflections of their experience attending the Autism, Emotional Well-being and Adolescence programme are shown in the thematic map in Figure 7.1.

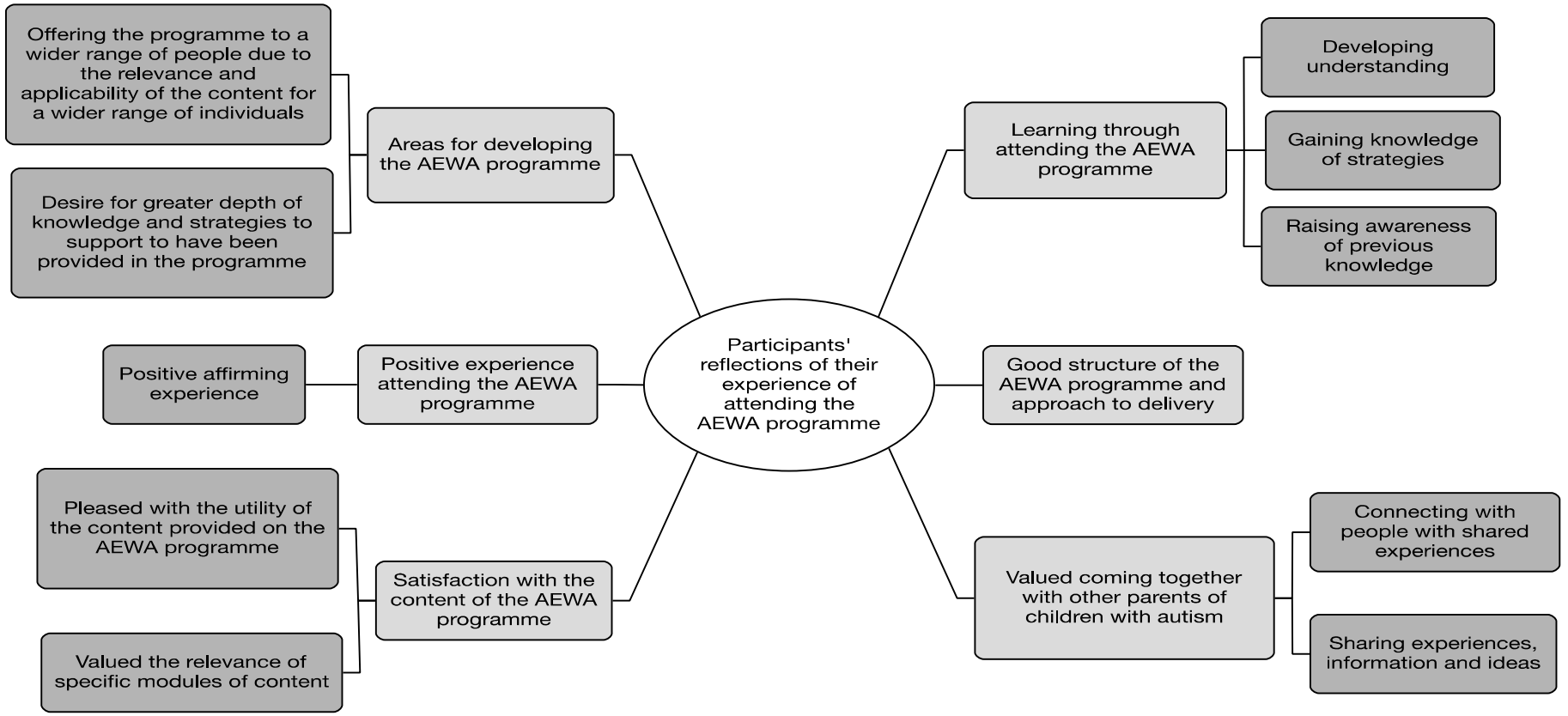

Figure 7. 1: *Thematic report of themes and sub-themes relating to participants' reflections of their experiences of attending the Autism, Emotional Well-being and Adolescence programme*

7.2.1 Satisfaction with the content of the AEWA programme

One of the most common occurring themes across the body of data, expressed by all participants attending the AEWA programme, was their satisfaction with the content delivered. This was illustrated in one participant's comments, who shared *"Because it was all so interesting (…) I found it really interesting, things I didn't know about at all…" (Parent 3, Line 249).*

Within the higher order theme, two sub-themes were evident:

i. **Pleased with the utility of the content provided on the AEWA programme -** *"I think it was all really helpful to be honest. I found it all really… there wasn't anything in particular that I thought I don't really get why they're doing that or… it was just, it was good" (Parent 2 – Line 192).*

ii. **Valued the relevance of specific modules of content** - *"The one thing I did find was the inappropriate and appropriate times [associated with sexualised behaviour], and things like that. That's one thing I really struggle with…" (Parent 4 - Line 594).*

Within the sub-theme valuing specific modules of content, a majority of participants reflected on the content around building parents' resilience. One parent shared *"It's the first course I've ever been on that they go, there's you, you need time for you, you need to understand that you're a person as well as a mum and a dad and a carer and all the rest of it. So that was quite nice, to recognise that" (Parent 4 – Line 447).* Content around promoting emotional well-being was also highlighted as particularly relevant for half of the participants interviewed and content around anxiety, managing stress and relaxation was also specifically identified as being valued by some participants. As illustrated by the example given, some participants suggested that they valued specific modules, as they were particularly relevant to their circumstances.

In summary, this theme indicated that there was a general feeling that all participants were satisfied by the content of the AEWA programme, which was often associated with the relevance and utility of the content and the modules included.

7.2.2 Learning through attending the AEWA programme

Closely linked to participants' satisfaction with the content was another commonly occurring theme. All participants interviewed indicated that through their experience of attending the AEWA programme, they had experienced some learning. One participant identified *"…That's something [support for a child in school] I wouldn't have known before. If I hadn't gone on the course, I'd have just been sat there with no knowledge". (Participant 4 – Line 957).*

Within the higher order theme of participants learning through attending the AEWA programme, three sub-themes were evident:

i. **Gaining knowledge of strategies**

"I really like the blob tree things as well so I think that will be really good to look at with him" (Participant 2 - Line 284).

ii. **Raising awareness of previous knowledge**

"Although I knew it already it really brought it home how much the anxiety really sits at the core of everything, and everything spins out from there (…)" (Participant 1 – Line 423).

iii. **Developing understanding**

"…[The Breakwell Cycle] it's something visual I can understand easily" (Participant 5 – Line 585).

In summary, all participants reflected that when attending the AEWA programme they had experienced some learning. Learning was also associated with gaining knowledge of a range of new strategies, highlighted across all participants. Participants also explicitly shared that the course had supported the development of their understanding in relation to the content. All participants reflected that they had come to the AEWA programme with some knowledge associated with the content, but the programme had helped them make links with the relevant knowledge they already had, bringing it to the forefront of their mind and, in some instances, reinforcing the importance of

what they knew. The impact of this is discussed by the researcher in relation to the next research question in the review of participants' subsequent experiences as a result of attending the programme.

7.2.3 Valued coming together with other parents of children with autism

A number of the participants identified coming together with other parents of children with ASD as a very positive aspect experienced in attending the AEWA programme. The reasons for this can be understood in the two sub-themes identified within this higher order theme:

i. Connecting with people with shared experiences

" …it's invaluable to know about other people's experiences because you know you're not the only one in the situation that you are…" (Participant 3 – Line 263).

ii. Sharing experiences, information and ideas

"*It's always handy hearing other peoples' stories, their personal stories and what's worked for them and what hasn't. That is always useful" (Participant 6 – Line 541)*.

In summary, nearly all participants valued how the AEWA programme brought them together with other parents of children with ASD. This can be understood when considering that all five participants who valued coming together with other parents of children with ASD, also suggested that had experienced feelings of isolation through comments such as *"because we do feel a bit on our own a lot of the time" (Participant 4 – Line 406).* It appeared that the participants particularly valued coming together with other parents of children with ASD as it offered the opportunity to connect with others with shared experiences and the opportunity to share experiences, information and ideas.

7.2.4 Positive experience attending the AEWA programme

Nearly all the participants suggested that attending the AEWA programme was a positive experience. This is illustrated in one participant's comments when asked about her experience attending the programme, she responded, *"I really*

enjoyed it. I have to say I loved it. (…) It didn't disappoint me at all. I just really enjoyed being there and listening to what people had to say (…). It was really positive and I'd love to do another one. (…), I really enjoyed everything" (Participant 3 - Line 235).

Within the higher order theme of positive experience attending the AEWA programme, the following sub-theme was identified:

i. **Positive affirming experience**

> *"It was nice to feel appreciated, it was nice to feel that you are doing a good job. Being a parent is a hard enough job, but being a parent to one autistic kid is hard" (Participant 4 – Line 549).*

For some participants, the positive affirming experience appeared to be linked to the sub-theme previously identified in that the programme raised their awareness of knowledge they had. For example, one participant shared:

> It's [the AEWA programme] helped a lot with that [when I question myself] actually. Because a lot of the things that I think of, I thought… that I thought… or even some of the things that I might have started to try already when you're being told, actually this is a good thing to do. It's like, oh okay, and it validates what you might have thought already. (Participant 2 – Line 325]

Nearly all participants reflected on attending the AEWA programme as a positive experience. As illustrated, reasons such as enjoyment of the programme were identified along with participants suggesting they were made to feel welcome, felt at ease and had a sense of belonging in the group. Linked to the positive experience, many participants made comments that reflected the AEWA programme was affirming for them. They suggested the programme acknowledged and reinforced what they already thought and what they had been doing, which had a positive effect on their affect.

7.2.5 Good structure of the AEWA and approach to delivery

Another strong theme across all participants was that participants felt the

AEWA programme had a good structure and they appeared to like the approach to delivery of the course.

Participants reflected positively on the overall structure of the course *"I think the whole thing was really well structured" (Participant 1 – Line 328).* Other participants reflected positively on other specific aspects of the structure of the course. Breaks in the course were identified in one participant's comments, *"I think the balance is right because we shared quite a lot of information but then we had breaks which gives you time to digest it have a bit of a breather and then come back to it" (Participant 3 –Line 401)*. Another participant identified that school staff being invited to join parents as a positive aspect of the programme's structure, *"It's nice that teaching assistants come, and teachers…" (Participant 4 – Line 478).* Having the opportunity within the course for parents to share information was also an aspect of the course structure that was reflected on positively by participants; for example, one participant identified in response to what he valued about the AEWA programme said *"going through a group discussion or everyone on the table's going through exercises, as to well, how would you approach this kind of issue?" (Participant 5 – Line 293).*

The approach to delivering the course information was also identified as a positive aspect of the course by participants. One participant identified that the activities were a positive aspect of the programme, "*Some of the activities were quite nice as well*" *(Participant 1 – Line 336)*. The approach of the programme facilitators was another aspect reflected on positively regarding the course delivery, for example one participant commented, "*I thought that it was delivered in a very down to earth easy to understand way. I took quite a lot from the two ladies that were delivering it" (Participant 6 – Line 508).*

7.2.6 Areas for developing the AEWA programme

This final higher order theme, that was equally strong compared to the others discussed, was all participants in their reflections of attending the AEWA programme identified that there were potential areas for developing the programme. For example, one area highlighted by a participant was the timing

of some aspects of the course in reaction to their child's stage of development. They commented:

> I *think the beginning of the course would have been right for me then [a few years ago] because when the children are younger you can start to think and put these strategies in place, as in how to help them. The thing about rewarding the children and not making them too big rewards, I was thinking I wish I'd done that earlier (…) Yes, I definitely think being on that course would have been better for me when XXXX was about 6 or 7. She's 10 now (Participant 3 – Line 308)*.

Within the higher order theme, two strong sub-themes emerged:

i. **Desire for greater depth of knowledge and strategies to support have been provided in the programme**

   "More on the transitions, I think. And I think the building resilience in adults…" (Participant 1 – Line 396).

ii. **Offering the programme to a wider range of people due to the relevance and applicability of the content for a wider range of individuals**

   "If you gave teachers the same course that I've just been on, and the Early Birds one, it would give them a complete understanding of what they're dealing with" (Participant 4 – Line 753).

All participants reflected that there were aspects of the programme that could be developed. For some participants this related to developing the content of the course so that there was more depth of information or strategies delivered, however, participants identified different areas, often related to what was pertinent to them. In reflecting on their experience of attending the programme, some participants reflected on the relevance of the programme for others, which included children directly, teachers and parents of typically developing children. This was identified as a theme for developing the programme moving forward.

7.3 Thematic Results: Participants' subsequent experiences as a result of attending the Autism, Emotional Well-being and Adolescence programme

The themes and sub-themes identified through the thematic analysis, identified as relevant to participants' subsequent experiences as a result of attending the Autism, Emotional Well-being and Adolescence programme are shown in the thematic map in Figure 7.2.

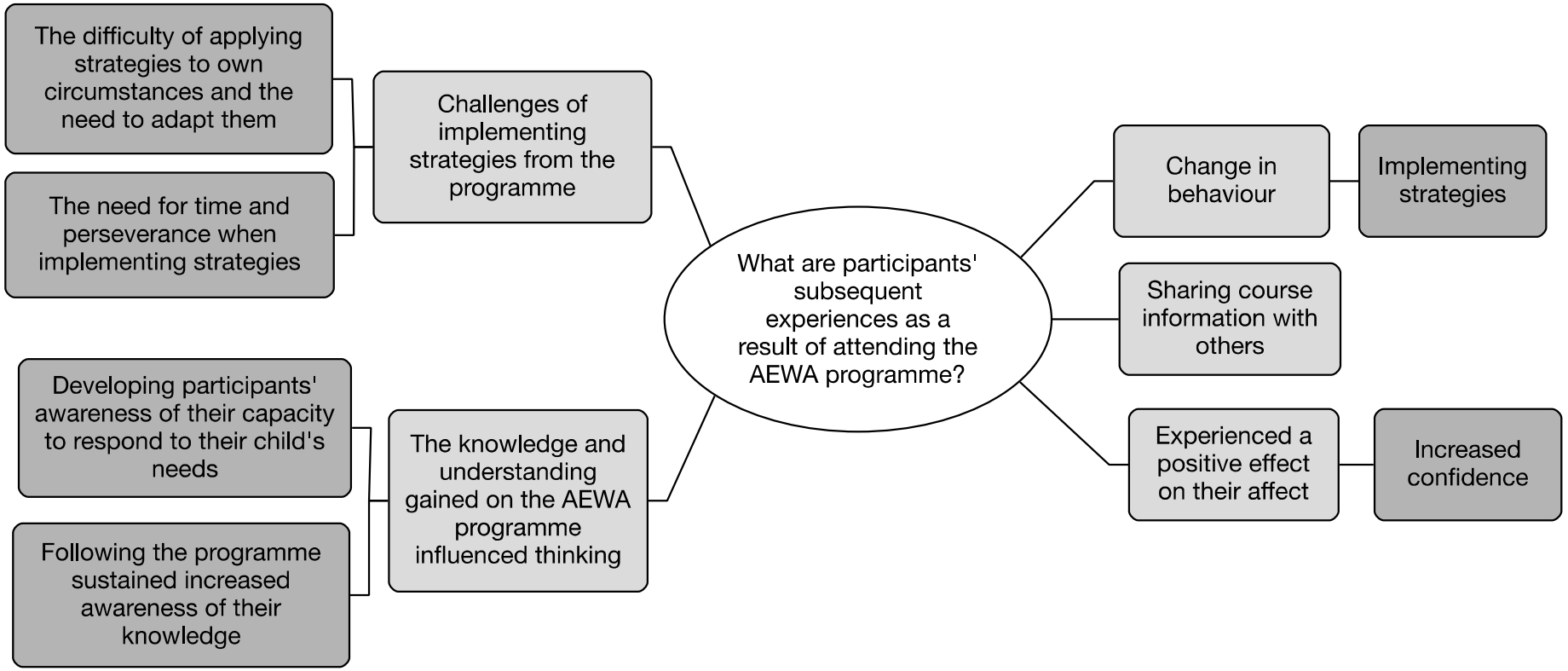

Figure 7. 2*: Thematic report of themes and sub-themes relating to participants' subsequent experiences as a result of attending the Autism, Emotional Well-being and Adolescence programme*

7.3.1 The knowledge and understanding gained on AEWA programme influenced thinking

All participants suggested that the AEWA programme had influenced their thinking since they had attended the programme. This is illustrated in the comment, *"…because that's something [promoting independence], which my wife and I have been talking about a bit, even since we got back from the course (…) we need to move him on and just give him little challenges that promotes his independence a bit" (Participant 5 – Line 353).* Participants also raised how the new knowledge gained on the AEWA programme was influencing their thinking in how they may approach supporting their child moving forward, *"I think we came to the conclusion that he really needs to meet her [his next teacher] in small doses to begin with, ease that transition step by step. Yes, problem solving step by step, like we said, little bits" (Participant 1 – Line 373).*

In reviewing the body of data, it was evident that the programme appeared to have influenced participants thinking in different ways. Two strong sub-themes were clearly identifiable within this higher order theme:

i. **Developing participants' awareness of their capacity to respond.**

"I think it made me think as well that actually I do know stuff and that I'm probably doing ok and yes things are difficult but I'm trying my best and that's all I can really do" (Participants 2 – Line 185).

ii. Following the programme sustained increased awareness of their knowledge

"I'm even more aware now of what I probably knew before, that other people have been telling me, is that I need 'me time' as well. (…) it has made me think that I need time when I'm not under pressure, and I can just do things that I enjoy doing" (Participant 5 – Line 495).

There was strong evidence across all participants that following their attendance on the AEWA programme, it had influenced their thinking. As

highlighted in the illustrative extracts the programme supported participants to draw upon previous knowledge to aid their thinking but also use the new knowledge gained. The impact of the programme influencing participants' thinking is considered in subsequent themes.

7.3.2 Experienced a positive effect on their affect

A majority of participants identified that the AEWA programme had supported a positive effect on how they were feeling. This is illustrated in the comments of one participant, *"I feel a lot less frightened" (Participant 6 – Line 766).*

Within the higher-level theme, was the sub-theme:

i. Increased confidence

> *"…it validates what you might have thought already, so it kind of gives you a little bit more confidence in what you are doing" (Participant 2 – Line 328).*

The majority of participants reflected that attending the AEWA programme had a positive effect on how they felt, specifically expressing they felt their confidence had increased. This higher-order theme closely links to the higher-order theme associated with the AEWA programme influencing participants' thinking. Some participants suggested that they thought they were more prepared as a result of attending the AEWA programme, which was supporting them to feel more confident. This link is illustrated by the comments of one participant:

> *…I felt a little bit calmer knowing that I've got a bit more knowledge, a few more tips, whereas before it was like if I'm asked this question or if this certain thing arises, what am I going to do? I was getting a bit blank, a bit kind of overwhelmed because XXX will overwhelm me sometimes with what his mood is or what he's going through (Participant 6 – Line 822).*

7.3.3 Change in behaviour

All participants suggested the AEWA programme had subsequently influenced a change in their behaviour, which is another theme closely linked to a change in thinking. This is illustrated in this comment *"I took from the whole course to be more mindful (…) I'm trying to think hang on a minute, I did the course, I'm going to try to do this differently to how I did it before. (…) Instead of snapping or getting a bit cross try to just be calm" (Participant 3 – Line 351).*

A strong sub-theme was identifiable within this higher order theme:

i. Implementing strategies

"The other thing I did learn from the course was (…) little rewards along the way, rather than having to wait for the big reward at the end, because they'll lose momentum waiting to get to the big one. So I have started doing little things like that" (Participant 4 – Line 654).

The majority of participants suggested that attending the AEWA programme had an impact on their behaviour. The change was predominantly in how participants responded to their child's needs and involved them using their knowledge and understanding gained on the AEWA programme, specifically linked to strategies.

7.3.4 Challenges of implementing strategies from the programme

All but one participant suggested that they were experiencing some form of challenge implementing some of the strategies identified on the AEWA programme. This is illustrated in the comments of one participant, *"So it was kind of difficult to put some of the techniques in place, because obviously each child is individual" (Participant 4 – Line 414).*

Two sub-themes emerged under the higher-order themes

i. The difficulty of applying strategies to own circumstances and the need to adapt them

"… different strategies and things. It's always hard to be able to come home and use them, especially with XXXX, you kind of have to maybe think a little bit outside the box and adapt it a little bit to suit him a bit better" (Participant 2 - Line 203)

ii. The need for time and perseverance when implementing strategies

Participant: "It's early days. (…) So to actually get him to sit down and do breathing exercises, or whatever it is, would be quite a struggle in the beginning (…)".

Interviewer: "…are there any [strategies] that you think you will be able to implement?"

Participant: "I think with perseverance, yes, …"

The majority of the participants suggested that they experience some challenges in implementing some of the strategies identified in the AEWA programme, which appeared to be associated with the challenge of applying the strategies to their own circumstances. Another sub-theme associated with the challenge of implementing strategies was the need for time and perseverance, as data was collected from participants two weeks after the end of the AEAW programme, it is acknowledged that participants had had limited time to try and implement some strategies.

7.3.5 Sharing course information with others

The final theme identified by half the participants was that they had been sharing the knowledge and understanding they had gained on the AEWA programme with others. This included with other family members, *"Yes. I actually did go through the Breakwell cycle and to tell him [son without autism] what he experiences is quite normal, it's trying to normalise things because he thinks he's the only one" (Participant 3 – Line 385);* other parents *"I've talked about it with people at school because they were really interested"* (Participant 3 – Line 616) and in one instance, it was identified that a person the participant

had shared it with, then intended to share the information wider *"my husband is a secondary school teacher and a lot of the stuff I came back with he was feverishly writing it down and taking notes so that he could take it back to his school and share it there*" *(Participant 6 – Line 501).*

7.4 Summary

In summary, the thematic analysis highlights that there were some common themes across the experiences of participants from whom qualitative data was gathered. The higher order themes and sub-themes identified in the thematic analysis and discussed in the reports have supported an understanding to be gained about participants' reflections on their experience of attending the AEWA programme, and participants' subsequent experiences as a result of attending the AEWA programme in response to the associated research questions. The following section will go on to consider the understanding gained through the qualitative design in relation to the quantitative results and in the context of wider research.

Chapter 8 – DISCUSSION

8.1 Introduction to the chapter

This chapter starts by revisiting the aims of this study, initially introduced in Chapter 2. It then goes on to give a synthesis of the study's findings in relation to each research question in turn. From the pragmatic stance taken in this study, the findings from the statistical analysis (Chapter 5) and the thematic analysis (Chapter 7) will be considered both together and separately as appropriate, to best address each question in turn.

The findings of this study will be discussed in relation to the relevant literature reviewed in Chapter 2, exploring possible interpretations and the significance of the findings in relation to understanding the impact of a parent programme focusing autism, emotional well-being and adolescence.

This chapter then moves on to an evaluation of the methodology used in this study before the implications of the finding of this study for practice are discussed. Finally, possible areas for future research are highlighted for consideration before this chapter concludes with a summary of what can be taken away from this study.

8.2 Summary of aims

Research suggests that parent programmes have previously been found to be an efficacious approach to meet a range of needs for individuals and their families, including those needs associated with autism. That having been said, the systematic review of literature in section 2.6 illustrated that there has been little research into the efficacy of the parent programmes as an approach to intervention when it is focused on promoting wellbeing and supporting individuals with autism through adolescence.

The research reviewed in Chapter 2, highlighted the need to promote the emotional well-being of young people with autism and support them through the possible challenges of adolescence. The AEWA programme offered an

approach to intervention to address this need. As this study is the first piece of research into the locally developed psychoeducation intervention, the aim of this study was to evaluate the AEWA programme. Parents' experience of attending the programme were explored along with parents' subsequent experiences as a result of attending. In exploring parents' experience as a result of attending the AEWA programme, a significant aspect of this study investigated the impact of the intervention on parents' perceived knowledge and confidence.

8.3 Discussion of Findings

8.3.1 Research Question One

Does the Autism, Emotional Well-being and Adolescence programme change parents' perceived knowledge and understanding of emotional well-being, potential challenges in adolescence and how they can support their child with autism?

The findings from both the quantitative and qualitative approaches used in this study to consider whether the AEWA programme increased parents' perceived knowledge. The bespoke measure used in the study was developed to measure parents' perceived knowledge specifically associated with the content of the programme. As indicated in section 5.2, the data gathered supported a rejection of the null hypotheses, indicating that the AEWA programme increased parents' knowledge. In exploring these results it was identified that all participants reported an increase in their knowledge of emotional well-being and strategies to promote, along with increasing their understanding of potential challenges in adolescence and how to support their child during this period.

These findings were supported by themes arising from the thematic analysis. A strong overarching theme identified indicated that all participants reflected that they had experienced some learning while attending the AEWA programme, which by definition is the acquisition of knowledge or skills. Associated sub-themes suggest that the learning participants' experienced could be associated with an increase in understanding in relation to the content, an increased

awareness of strategies to support their child with autism and an increased of their awareness of knowledge they already had.

As indicated, a sub-theme arising from the qualitative data suggests attending the AEWA programme raised participants' awareness of relevant knowledge they already held coming to the AEWA programme. This highlights that participants came to the programme with relevant subject knowledge, which has previously been identified in research (Hounslow, 2012). Raising awareness of prior subject knowledge is important, as it is a mechanism to support learning, with the acquisition of new knowledge determined by the prior subject knowledge a person has, that has been activated (Schmidt, 1993).

Similarly to previous research, this study provides evidence that parent programmes can be an efficacious approach to increasing the perceived knowledge of parents of children with autism (Hounslow, 2012; Anderson, et al., 2006; Frea and Hepburn 1999; Cordisco et al. 1988). Importantly, this study builds on from the current body evidence, suggesting that through a parent programme, parents of children with autism can be supported to develop their knowledge about emotional well-being; the potential challenges during adolescence that can impact on emotional well-being and knowledge of how they can support their child with autism in these areas of potential need.

It was identified that the AEWA programme developed participants' awareness of strategies to support their child. The programme provided information on evidence-based strategies that focused on developing specific skills derived from behavioural and cognitive approaches, a key feature of effective parent education programmes (Moran et al., 2004).

The AEWA programme specifically focused on developing parents' knowledge relating to child development associated with autism, emotional well-being and adolescence. This study has demonstrated an increase in perceived knowledge, which has been found to have a moderate correlation with actual cognitive learning (Sitzmann, Ely, Brown, and Bauer, 2010).

Increasing knowledge about child development has been identified as an effective practice in interventions for parents (Moran et al., 2004). This can be understood from an ecological perspective (Brofenbrenner, 1977, 1979) as the family is part of the microsystem, the most influential system on a child's development (Bronfenbrenner, 1986). Therefore it could be viewed that increasing parents' knowledge through the AEWA programme has the potential to improve the developmental context of a child, by helping parents better understand how to support the development of their child.

As discussed, parent programmes have the potential to have a positive impact on both parent and child outcomes. Developing parents' knowledge linked to autism has been found to promote better social, emotional and mental health outcomes for children (Forehand et al., 2013; Barlow et al., 2010). In addition, it has been found to reduce parental, anxiety, stress and distress (Farmer & Rupet, 2013; Tonge et al., 2006; Izadi-Mazidi, Riahi & Khajeddin, 2015). Although the current study has not explored the impact of the programme on these parent and child outcomes, it is identified that such outcomes are an area for future exploration.

In summary, the findings from this study support previous research that indicate parent education programmes are an efficacious approach to increasing the knowledge of parents of children with autism. Unlike previous research, this study has shown that through a parent psychoeducation programme that focuses on autism, emotional well-being and adolescence, parents' perceived knowledge in these areas can be developed. As illustrated in the systematic review of research in section 2.6, relatively limited research has previously explored the potential of parent programmes in this area. Given the potential impact of developing parents' knowledge on parent and child outcomes, this is important, particularly given the evidence of a need for support in these areas.

8.3.2 Research Question Two

Does the Autism, Emotional Well-being and Adolescence programme change parents' perceived confidence in promoting the emotional well-being of their child with autism and supporting them through potential challenges in adolescence?

The findings of both the quantitative and qualitative approaches were used to consider whether the AEWA programme increased parents' perceived confidence in supporting the emotional well-being of their child with autism.

The survey developed for the study, measured participants' perceived confidence in their ability to promote the emotional well-being of their child with autism and support them through the potential challenges of adolescence. As identified in section 5.3, the data gathered supported a rejection of the null hypotheses, providing evidence that the AEWA programme can promote the confidence of parents in their ability to support their child with autism in these areas. These findings were also supported in the interpretation of the qualitative data in the thematic analysis; a higher order theme identified was that the AEWA programme had a positive effect on participants' affect, with increased confidence identified as a sub-theme.

Similarly to the findings of previous research (Barlow et al., 2012), the evidence from this study suggests that a parent programme can improve parents' confidence in their ability to meet the needs of their child. Specifically, this study supports previous findings that when a parent programme includes content that considers the complexities of the needs associated with autism, it can be an efficacious approach to promoting the confidence of parents (Tellegen & Sanders, 2014; Cutress & Muncer, 2014; Farmer & Rupet, 2013; Dillenburger, Keenan, Gallagher & McElhinney, 2004; Engwall & MacPhearson, 2003).

This study builds on the current body of evidence, suggesting that the AEWA programme can be used to increase parents' perceived confidence specifically in relation to promoting the emotional well-being of their child with autism, and

perceived confidence in supporting their child through the potential challenges of adolescence.

Promoting parents confidence is important as Self-Efficacy Theory (Bandura, 1977, 2004) tells us that when challenged, individuals are more likely to engage in things when they are more confident that they are able to accomplish their desired outcomes. It is particularly important to promote the confidence of parents of children with autism given parents have poorer well-being outcomes (Place, 2016, Karst & Van Hecke, 2012; Rao & Beidel, 2009) and report lower self efficacy in their parenting (Weiss, Tint, Paquette-Smith & Lunsky, 2015). Consequently, promoting parents' perceived confidence, their individual appraisal of their capabilities to meet their child's needs, has the potential to increase the likelihood of them implementing interventions to promote their child's emotional well-being, even in the face of adversity.

In exploring the quantitative results, it is notable that there was an exception in the data. One participant's data indicated their confidence in promoting the emotional well-being of their child had not altered as a result of attending the AEWA. The same participant's data also reflected that their confidence in supporting their child through adolescence had actually slightly decreased following their attendance of the AEWA programme.

The conscious competence-learning concept could possibly explain the finding that in some instances the programme may not have a positive impact on parental confidence. This theoretical understanding suggests that during learning participants sequentially progress through the following four stages: unconscious incompetence, consciously incompetent, conscious competence and unconscious competence. It is possible that the new knowledge gained on the AEWA programme highlighted the potential challenges the participant faced in supporting their child with autism, raising their consciousness of their possible incompetence.

The variation in confidence outcomes experienced by participants could possibly be explained by the understanding that self-efficacy, which can be viewed in relation to confidence, can be affected by a range of different variables (Bandura,

1997). It has been suggested that confidence is influenced by imaginable experiences, involving an individual ability to visualise themselves behaving successfully (Maddux, 2009) and an individual's emotional state (Bandura, 1997), factors which may have varied amongst participants.

In summary, the findings of this study support previous research that indicates parent education programmes can be an efficacious approach to promoting parents' confidence in their skills to meet their child's needs. Building on from previous research, this study has provided evidence that the AEWA programme can be used to increase parents' perceived confidence specifically in relation to promoting the emotional well-being of their child with autism and perceived confidence in supporting their child through the potential challenges of adolescence. Again this is an area that has previously had limited attention in the research literature, as indicated in the review of research in section 2.6.

The following two research questions represent a shift in the focus of the study, moving on from identifying the impact of the AEWA programme on specific measurable outcomes, which have been discussed in section 8.3.1 and 8.3.2 to exploring parents' reflections on their lived experiences. These exploratory research questions will be addressed by identifying the key themes arising from the thematic analysis and discussing them in relation to relevant research. It should be noted that some themes have been discussed in relation to previous research questions, so will not be considered again. It is important when reviewing these themes to consider they came from a small number of participants, a limitation that will be discussed later (section 8.4).

8.3.3 Research Question Three

What are participants' reflections on their experience attending the Autism, Emotional Well-being and Adolescence programme?

8.3.3.1 Satisfaction with the content of the AEWA programme

A strong overarching theme identified in the qualitative findings indicated that participants were satisfied with the content of the AEWA programme, which focused on promoting learning and skill development associated autism,

emotional well-being and adolescence (see section 3.8 for an overview of the programme). Associated sub-themes suggest that participants valued the relevance of specific modules of content and perceived the content as being of utility to them. These findings could be interpreted that parents of children with autism who are approaching adolescence have an actual need for such information.

It is understandable that content focusing on emotional well-being was viewed as relevant and useful given a significant number of parents of children seek help for their child's mental health (Green et al., 2005) with the prevalence of poor mental health outcomes for young people with autism commonly co-occurring (Vasa et al., 2014; van Steensel, Bögels, & Perrin, 2011).

Identifying that content focused on developing the understanding of the potential challenges in adolescence and approaches to overcome them is of value to parents is also important. Firstly, as discussed, there is a lack of research into the methods to support young people with autism during this time (Matson, Mahan and Matson, 2009). Additionally, the review of the literature has illustrated that adolescence is a potentially challenging period, with research suggesting it is a time in which increased negative emotional well-being outcomes for all young people and, in particular, those with autism (de Bruin et al., 2006).

It could, therefore, be interpreted that the AEWA programme offers a useful and relevant approach to intervention to support young people with autism and their families to manage the demands of daily life as the challenges change, an area that has previously been identified priority for research by key stakeholders (Pellicano, Dinsmore & Charman, 2013).

8.3.3.2 Structure and approach to the delivery of the AEWA programme

It was evident in the qualitative data collected that participants perceived the structure and approach to delivery in the AEWA programme as good. Participants commented on different aspects of the structure and delivery of the AEWA programme suggesting they valued different things.

Moran et al. (2004) identified that a clear structure and fidelity to the intervention are important for parent interventions to be effective. The AEWA programme was structured with a manual guiding the structure and approach to delivery and there was strong fidelity to the intervention for the programme from which participant data was collected (see section 4.3.2).

Some participants identified the group discussions as a valued part of the structure. During the AEWA programme, parents were actively encouraged to participate in discussions and contribute their own experiences and included some small group activities. Working collaboratively in this way, with parents being viewed as experts in their own child, along with the social aspect of working with groups of peers has been identified as important facets in supporting the effectiveness of parent interventions (Moran et al., 2004).

There has been a call for further identification of what works in relation to parent programmes and in what circumstances (Moran et al., 2004), particularly in relation to parent programmes used to support parents of children with autism (Schultz, Schmidt, & Stichter, 2011).

In summary, this study has identified structure and the approaches to delivery are important aspects of interventions for parents, affecting participant experience. Evidence suggests the structure and delivery of the AEWA programme was valued by participants. It is known the intervention incorporated some variables that support parent programmes to be effective, however, it is recognised that the specific aspects of the structure and delivery valued requires further exploration.

8.3.3.3 Valued the experience of coming together

The study has found evidence to suggest that participants valued coming together with other parents of children with autism. The opportunity to connect with parents with common experiences was specifically highlighted as a sub-theme along with the opportunity to share experiences, information and ideas being a valued part of the programme. These findings provide confirmatory evidence of previous research that has highlighted the positive impact of parent

programmes as a mechanism for providing parent-to-parent mutual support (Murphy & Tierney, ND; Cutress & Muncer, 2014; Farmer and Rupert, 2013; Patterson, Smith & Mirenda, 2011, McConachie, & Diggle, 2007).

Valuing the opportunity to come together could be explained by the findings that families of children with autism are at increased risk of isolation and social exclusion (Banach et al., 2010). Participants that valued coming together with other parents of children with autism also suggested that they had experienced feelings of isolation through comments such as *"because we do feel a bit on our own a lot of the time" (Participant 4 – Line 406).* Parent programmes for families of children with autism have been found to reduce feelings of isolation (Catalano, Holloway and Mpofu, 2018). Building on this, it could be interpreted that the AEWA programme provided an opportunity for social connectedness, a sense of kinship and belonging amongst participants who had experienced a sense of isolation.

8.3.3.4 Areas for developing the AEWA programme

Despite participants reflecting positively about their experience of attending the AEWA programme, 'areas for further developing the programme' was an overarching theme evident in the qualitative data. The programme is in its infancy as an approach to intervention, so identification of areas for development are important to support the future growth of the programme.

Different areas for developing the course were identified by participants, which included the timing of the information in relation to a child's development and the time of day the course was offered, which are recognised as factors influencing the effectiveness of interventions (Moran et al., 2004).

A sub-theme suggested that participants desired a greater depth of information and strategies, with the specific areas identified varying across participants. The variation could be explained by the understanding that individuals with autism are a heterogeneous population, with individuals presenting unique profiles of diverse strengths and needs. As a result, there is likely to be differences in what is relevant and of interest to parents. The broad age range of children targeted by

the AEWA programme (parents of eight to thirteen year old children and young people) may also account for the variance in the range of topics participants sought to gain a greater insight into. For example, a key transition time is the move from primary to secondary school, which occurs at eleven years old, so information associated with transition may be of particular interest for parents whose children are eleven years or younger who have not yet made the transition.

The variations in responses to the areas participants would like greater focus upon, raises the challenge faced by professionals of how they meet a broad range of needs through group intervention. Possible consideration for the future development of the programme may include instruments in which the needs of participants can be identified such as Target Monitoring Evaluation (Dunsmuir, Iyadurai, Brown & Monson, 2009). Such an instrument would support participants to me make explicit their objectives for facilitators to respond to, although this would require flexibility in the programme as to what is delivered. An alternative consideration is an approach to group intervention developed by a team of EPs known as Adaptive Coaching (Bridge, Ashton-Jones & McLean, 2018). Instead of being guided by a curriculum, this approach to intervention offers a flexibility, in which EPs respond to the needs of the group as they arise in discussion drawing on the professional knowledge base in psychology.

A sub-theme that could be perceived as reflecting a positive view of the AEWA programme was participants suggested that in developing the AEWA programme, it should be offered to a wider range of people due to the relevance and applicability of the content for a wider range of individuals. Suggestions included delivery to children directly, teachers and parents of typically developing children.

Considering this finding, how the AEWA programme could be adapted to meet the needs of others beyond parents with autism is an area for future consideration. Parents of typically developing children with social and emotional needs may benefit from the AEWA programme, as a parent programme with some small adaptions. There is also the possibility to provide the AEWA

programme for school staff separately to support them to promote wellbeing and support young people manage the potential challenges of adolescence.

Current policy is focused on how to promote emotional well-being in the context of education, reinforcing the view of participants that information in this area is broadly relevant (Public Health England & Children and Young People's Mental Health Coalition, 2015). The cost-benefit of using the adapted versions of the AEWA programme relative to other approaches would need consideration and has implications for future research. It is also acknowledged that broader LA policy will also be influential in making decisions about the delivery of interventions such as the AEWA programme, which will be discussed in the later section 8.6.3, implication for LA and policy.

8.3.3.5 Positive experience

The final overarching theme to be discussed is that, overall, participants suggested that attending the AEWA programme was a positive experience. The positive aspects of the programme previously identified in the themes are likely to have contributed to participants' positive interpretation of their experience attending the programme.

Specifically, the positive affirming experience for participants of the AEWA programme was identified as a sub-theme. As previously discussed, parents came with relevant knowledge to the AEWA programme. Highlighting the resources parents already had through the programme content and the sharing of experiences amongst participants appeared to be an experience that was reflected upon positively as having an emotional and encouraging effect on participant feelings. This supports previous research, which suggests parents of children with autism receive validation from peers through group interventions (Catalano, Holloway and Mpofu, 2018).

8.3.4 Research Question Four

What are participants' subsequent experiences as a result of attending the AEWA programme?

The fourth and final research question focuses on exploring the subsequent experiences of parents as a result of attending the AEWA programme. As indicated from research questions one and two, following the programme parents' experienced an increase in their knowledge and confidence after they attended the programme. Additional themes arising from the qualitative data will now be explored.

8.3.4.1 The knowledge and understanding gained from the AEWA programme influenced thinking

A strong overarching theme was participants' thinking was influenced by the knowledge gained as a result of attending the AEWA programme. It is likely that new knowledge gained from the programme and the knowledge that was reinforced, influenced participants' thinking in how they respond to their child's needs. Linked to this, the sub-theme sustained awareness of information indicated that following the programme, participants had maintained their awareness of information that they already had. For example, it made them think about things they knew they should be doing, but had not been.

Changes in thinking are important; it is known from cognitive-behavioural theory that changes in thinking can affect feelings and have implications for behaviour. These are both overarching themes arising in this study that will be discussed.

8.3.4.2 Change in behaviour

It appears that parents were supported through the AEWA programme to change their behaviour, specifically to implement strategies to support their child's needs. It is likely that factors previously discussed such as parents' increases in knowledge, confidence and awareness of their capacity to respond to their child's needs, may have been mechanisms that promoted parents' behaviour changes.

The findings of this study support previous studies that have suggested that parent programmes are successful approaches to intervention to change the behaviour of the parents of children with autism (Forehand et al., 2013).

Significantly, building on from previous research, this study has shown that a parent programme such as the AEWA programme, can be used to support parents of children with autism to change their behaviour to implement strategies to meet needs associated with emotional well-being and support through the potential challenge of adolescence.

Although child outcomes have not been a focus of this current study, it is known that changes in parents' behaviours are important as they are recognised as having a significant influence on their child's development (Bronfenbrenner, 1977, 1979). The AEWA programme included information about strategies parents could use to promote the emotional regulation and resilience of their child with autism. It is known that children can learn to use such strategies if parents use their knowledge of strategies to scaffold and model them (Bandura, 1977; Vygotsky, 1978). This is important as previous research indicates developing children's skills in the areas targeted by the AEWA programme has the potential to directly or indirectly promote emotional well-being (Artuch-Garde et al., 2017; Berking & Wupperman, 2012; Hu et al., 2014) and other positive outcomes for children and young people (Mackay et al., 2017; Burić et al., 2016; Graziano et al., 2007).

8.3.4.3 Positive effect on participants affect

As already alluded in response to research question two, a theme arising from the data suggested that attendance on the AEWA programme has the potential to have a sustained positive effect on participants' affect. Participants suggested they felt more prepared, more confident and less frightened. This is an important finding considering poor mental health outcomes have been associated parents of children with autism (Place, 2016; Karst & Van Hecke, 2012; Rao & Beidel, 2009).

8.3.4.4 Sharing course information with others

A theme emerging in this study was parents were sharing the knowledge they gained on the AEWA programme more widely with other people outside of the programme. This sub-theme could be viewed as building on from the previous theme discussed, that the programme should be offered to a wider range of

people due to the relevance and applicability of the content to different individuals.

Parent programmes have been recognised as a way of increasing access to psychological intervention (McConachie et al., 2013). The evidence from this study suggests that the sharing of psychological knowledge to support understanding of needs goes beyond just the participants. Participants identified they were sharing information with other key people in their child's microsystem, including other family members and educational professionals, which has the potential to further support the developmental context of the child. Sharing psychological knowledge widely is valuable considering the low number of individuals who would benefit from intervention to promote emotional well-being access appropriate support (Green et al., 2005).

It was also evident that as a consequence of attending the AEWA programme participants were sharing information from the programme with others, to support individuals without a diagnosis of autism. This could be interpreted that participants view information about promoting emotional well-being and supporting young people through the potential challenges of adolescence as relevant and useful for individuals beyond parents of children with autism. A possible explanation for this is that although the programme targeted parents of children with autism, it is underpinned by psychological theory and theory-driven good practice approaches, which are not purely autism specific.

The AEWA programme was developed for parents of children with autism; consequently, other parents of children with similar needs associated with emotional well-being and adolescence but without autism did not have access to the programme. It is argued that there is a privilege in stratifying services to families of children with autism, which presents a risk to other individuals being denied access service to address their needs, which has previously been discussed by Timinni (2017).

8.3.4.5 Challenge of implementing strategies

Parents experienced challenge implementing the strategies they had learned after receiving the AEWA programme. It appeared that parents experienced difficulties in applying some strategies to their own circumstances suggesting that in some instances they needed to adapt them.

As individuals with autism make up a heterogeneous group, it is conceivable they will need an individual approach to interventions based upon their individual needs. This was recognised in the comments of one participant; *"So it was kind of difficult to put some of the techniques in place, because obviously each child is individual" (Participant 4 –Line 414).* Tailoring strategies for an individualised approach appropriate for their child is part the nature of the challenge for parents of children with autism. This again highlights the difficulty in meeting a range of needs through a group intervention, such as the AEWA programme, and raises a need to assess the cost-benefit of a group intervention when compared to an individualised approach.

The challenge of implementing an intervention for individuals based on their individual circumstances does raise a question about the overall effectiveness of the AEWA programme. This suggests, not surprisingly, that not all strategies from the programme were of equal use for every parent. Nevertheless, the finding that participants reported that they needed to adapt the strategies suggests they had the knowledge and confidence to make adaptions to meet the requirements of their own context.

A possible future development of the AEWA programme could be offering participant on the programme the opportunity in the sessions to explore possible ways they could implement strategies considering their own contexts taking an action plan approach, providing facilitation of the sharing ideas amongst the group to support.

A sub-theme was identified that there was a need for perseverance and more time to implement strategies. Participants alluded to constraints of the limited time available to implement strategies before data was gathered in the weeks

following the AEWA programme, for example when asked about implementing strategies from the programme one participant responded: "*there's not been a lot of time to…" (Participant 5 - Line 418).* Given the limited time available before the data was collected, participants are unlikely to have had opportunities to use their new knowledge and skills learned on the AEWA programme to mastery, which is likely to have affected participants' confidence (Bandura, 1997).

Given the identification of the need for time and perseverance, consideration could potentially be given to provide a follow-up session after a suitable period of time, which allows parents to use their skills to implement the strategies identified. This would potentially provide an opportunity for parents to reflect on their successes and challenges and bring them back to the group context for support in the areas required.

In summary, the qualitative data has provided an insight into participants' experience following their attendance on the AEWA programme. The study suggests that a parent psychoeducation programme focusing on autism emotional well-being and adolescence has a positive impact on parents' thoughts, feelings and behaviours following their participation. It appears many experiences following the programme could be viewed as positive but it raised the challenge of applying theory gained in a group, to the individual's context.

8.3.5 AEWA parent programme as an intervention to support the process of change

The aim of the AEWA programme was to promote change in parents to benefit the developmental context of the child and facilitate change for them. The AEWA programme aimed to do this by facilitating change in parents' knowledge and confidence, which as discussed in section 2.5.10 are key mechanisms to support behaviour change. Through supporting parents it was anticipated they would be better equipped to promote the emotional wellbeing of their child with autism, with a particular emphasis on adolescence. As discussed, this is of particular importance, given the risk of poor mental health outcomes for young people with autism.

This primary study, evaluating the AEWA programme has established that there is promising evidence to suggest that the programme has the potential to facilitate change for parents. The findings from this study suggest that the intervention facilitated change in parents' cognitions, feelings and behaviours. The qualitative findings also highlight elements from the AEWA programme that potentially supported the mechanisms underpinning the process of change relating to the content and delivery of the programme. It is also evident, from the themes identified in the exploratory part of the study, that the experience of attending the AEWA programme is valued by participants, more generally, relating to aspects of social connectedness that can be associated with participating in a group intervention.

Possible elements and mechanisms that have supported the change process are provided in a visual representation in Figure 8.1.

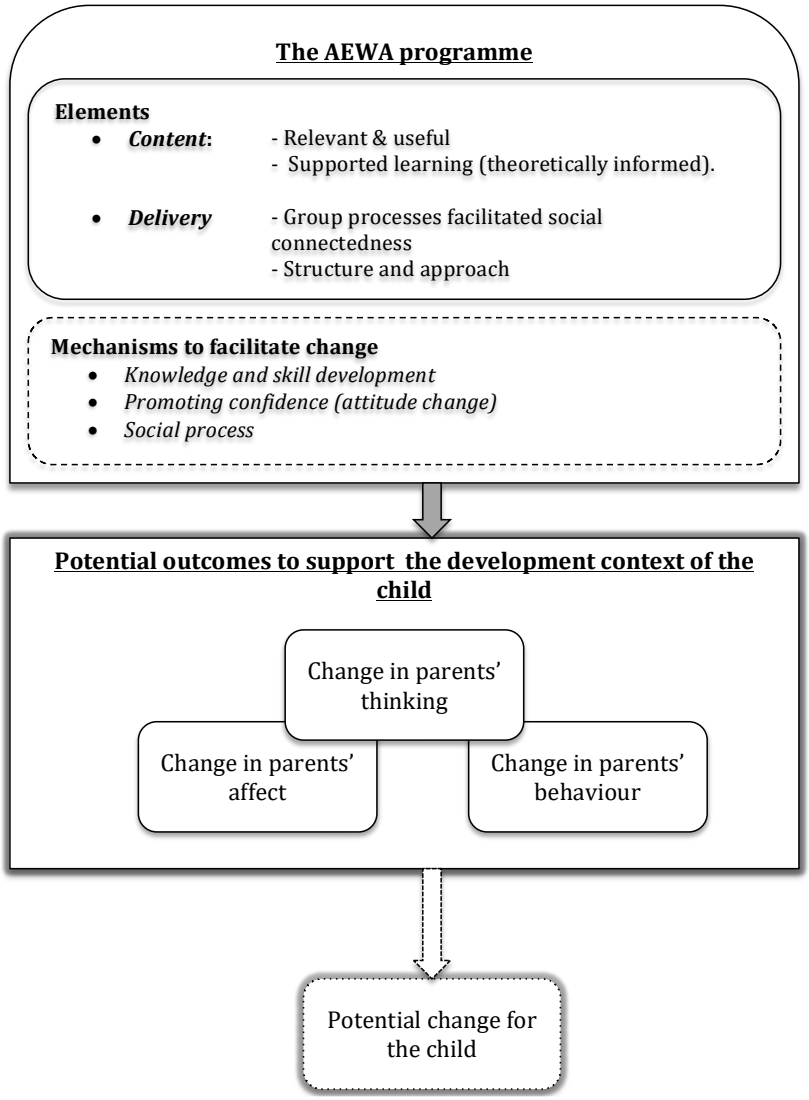

Figure 8. 1: Visual representation of the process of change supported by the AEWA programme

8.3.5.1 Knowledge and skill development supported the process of change

The results of both the quantitative and qualitative design used in this study suggest that the AEWA programme developed parents' knowledge, known to be a key mechanism to promote behaviour change, as it guides parents' attitudes and behaviours (The National Academies of Science, Engineering and Medicine, 2016).

The content and delivery of parent programmes is of central importance to support the acquisition of knowledge (Whittaker & Cowley, 2010). As discussed, many elements associated with effective parent programmes have been incorporated into the AEWA programme and could potentially have supported the development of parents' knowledge.

Effective interventions have been found to meet the needs of the targeted population (Whittaker & Cowley, 2010). As noted, the AEWA programme was developed by EPs specifically in response to an identified need to promote the emotional wellbeing of young people with autism during early adolescence. The programme content was specifically developed and tailored to do this, using psychological theory and theoretically informed approaches outlined in section 3.8.4.

A key finding from the qualitative analysis suggests that parents valued the content of the AEWA programme and viewed it as relevant and useful (see 8.3.3.1), which as discussed is understandable given the risk of poorer mental health outcomes for young people with autism (Vasa et al., 2014; van Steensel, Bögels, & Perrin, 2011). This is important because as highlighted by Moran et al. (2004), for any parent programme to have a chance of being effective at promoting parents' knowledge, successful recruitment to the programme and retention is required, which is supported by content that is identified as relevant and valued by participants.

8.3.5.2 Promotion of confidence supported the process of change

As noted, the results of this study are promising in that they suggest that the AEWA programme promoted parent confidence, with the potential to support self-efficacy and facilitate behaviour change.

The content , structure and approach to the delivery of the programme are likely to have contributed to the promotion of participants' confidence. As illustrated in 8.3.3.5, it was suggested that attending the AEWA programme was a positive and affirmative experience for participants. The AEWA programme incorporated a range of group activities and facilitated active discussion, encouraging participants to contribute to share their experiences and ideas throughout the programme. By encouraging participants to be active partners, recognising the skills and qualities they bring may have promoted their confidence as it has been previously found this approach supports parents to feel valued (National Academies of Science, Engineering and Medicine, 2016). The social processes facilitated by the approach to delivery of the programme are also likely to have promoted participants' confidence through the validation from peers which has been found in group interventions (Catalano, Holloway & Mpofu, 2018).

8.3.5.3 Social connectedness supported the process of change

Exploratory data suggested that beyond the content, the facilitation of the AEWA programme as a group intervention contributed to its success. As discussed in section 8.3.3 Participants indicated they valued the opportunity to connect with other participants; the structure and delivery of the programme; and attending the programme was perceived to be a positive experience.

Having the opportunity to connect with peers has previously been identified as an important element for effective group intervention (The National Academies of Science, Engineering and Medicine, 2016). The social connectedness that parent programmes provide is promoted by its delivery (Whitacker & Cowley, 2010). The structure and delivery of the programme along with the group facilitation skills of those delivering the intervention determine the extent to which participants have the opportunity to receive peer support from one

another, for a collective experience and to reduce feelings of isolation. This is particularly important for the participants in this study because as discussed, families of children of autism frequently experience higher levels of isolation (Banach et al., 2010).

To promote effective interventions, skilled practitioners have been identified as being essential in facilitating the group intervention (Whittaker & Cowley, 2010). The AEWA programme was developed and facilitated by qualified and experience EPs. Training to become an EP involves the development of group facilitation skills, which are frequently and widely utilised in the role. The programme may have benefited from the group facilitation skills to encourage peer relations to be fostered amongst the group. For example, the programme included the provision of discussion activities, group tasks and time for networking throughout the programme.

8.3.6 Summary of findings

This primary study, evaluating the AEWA programme has increased the understanding of how attendance on the AEWA programme influenced participants' experiences both during and after the programme.

The analysis suggests the programme was received well by participants, which can be accounted for by many of the positive overarching themes, although it is acknowledged there are areas to consider in which the programme could be developed. The results show potential promise that the AEWA programme can support change for parents in their thinking, feelings and behaviour which has the potential change in the development context of their child.

This study has provided an insight in to the mechanisms that can explain the process of change that have been supported by the AEWA programme, which have included the development of participants' confidence and knowledge, along with the social process. As discussed elements that have been associated with effective parent programmes as an approach to intervention, incorporated in the AEWA programme linked to the content and delivery can be viewed as possibly supporting these mechanisms.

The findings suggest participants' experience of the programme are closely related to their subsequent experience as a result of attending the programme. First, participants suggested that the programme influenced a change in their thinking, feelings and behaviour. Second, the identification that the course is relevant for a wider range of individuals is echoed in the identification that participants are sharing information with others. Third, the challenge of meeting a range of needs in a group context (section 8.3.3.4) was again echoed in the suggestion that there was a challenge for parents in implementing the strategies from the programme, due to the variation in their individual contexts.

The findings discussed have possible implications for developing the programme, future research and for professional practice, which will be considered below.

8.4 Methodological Evaluation

8.4.1 Introduction to the section

In previous sections, general issues affecting the quality of quantitative and qualitative designs were identified and considered in relation to the current study. The study goes on to review particular key issues that have impacted upon the quality of this study that need to be considered before the implications of the findings are discussed.

8.4.2 Research design

Researcher decisions influence the outcomes of a study. For example, the research questions chosen are a unique feature in a study and will determine what is explored and ultimately have consequences for what is found. It is recognised that other researchers may have made different decisions about the research questions perceived as pertinent to an evaluation of the AEWA programme.

This study did not investigate outcomes for children or parent outcomes associated with well-being. While this may be perceived as a potential limitation, the outcomes measured were guided by the evidence that interventions which equip parents with a greater understanding of child development and promote their confidence in their parenting skills have been found to be most effective (Social Mobility Commission, 2017).

One of the key outcomes explored in this study was participants' perception of their own knowledge pre- and post-intervention. Though it is known that perceived knowledge and actual knowledge are separate constructs, with a debate in research as to whether gains in perceived knowledge correlate with gains in actual knowledge gain; Sitzmann, Ely, Brown, and Bauer (2010) have found there to be a correlation between self-assessed knowledge and actual cognitive learning, although acknowledged to be small to moderate.

The intervention outcomes measured in this study were not considered in the context of the complex systems, which individual participants were part of. For example, in the quantitative design, participants did not have the option to raise

factors influencing their responses on the survey, nor were mediating variables associated with perceived knowledge and confidence investigated. While this maybe viewed as a limitation of this study, the use of mixed method approach did go some way to overcome this, as participants were encouraged to share relevant experience in semi-structured interviews, to provide context to their answers. Future research may consider investigating further participants' prior experiences coming to the programme that could potentially influence outcomes.

8.4.3 Inference Quality

Inference quality is a term used in mixed methods to incorporate issues of internal validity discussed in the qualitative design and credibility considered in the qualitative design (Teddlie & Tashakkori, 2009). The inference quality of this study will now be addressed considering how well the outcomes found can be attributed to the AEWA programme by identifying confounding variables along with evaluating the credibility of the qualitative design.

It is known that children with autism make up a heterogeneous group, which will result in parents having within-group variations in their experiences coming to the programme. This has implications for the inferences quality, which will now be discussed and the generalisation of the findings discussed in section 8.4.6 .

In this study, participants' histories were diverse, as illustrated by the personal details in Table 4.1 and the varied support participants were receiving from professionals currently and historically detailed Table 4.3. The researcher was unable to control for variations and other factors influencing participants' environmental context with factors associated with an individual's history recognised as a threat to the inference quality. It is therefore important to view with care the multiple interferences about the outcomes attributed to the AEWA intervention linked to changes in knowledge, confidence, thinking, affect and behaviour provided in the account, as they may have been caused or mediated by other factors not considered. However, as detailed in section 6.4, defensive

action was taken in this study to support the inference quality to support the confidence in the inferences that have been made.

Researcher bias is identified as another potential risk to the quality of the study. The researcher is currently employed by the EPT responsible for developing the AEWA programme and has a professional relationship with the EPs who delivered the intervention. The researcher acknowledges their circumstance could have a potential positive bias in their evaluation of the AEWA programme. Although defensive actions were taken to support the credibility and trustworthiness of the design as discussed in section 6.4, the possible researcher bias is acknowledged. Member checking with participants involved in the study is a possible consideration for future research.

8.4.4 Content Validity

Content validity in the context of this study refers to the extent the measures used evaluated the achievement of knowledge and confidence specifically related to the content of the AEWA programme. Due to difficulties identifying an appropriate established measure that would have high content validity, as discussed the researcher made the decision to develop a bespoke measure for use in this study. The content of the AEWA programme was used to guide the items included in the measure, supporting a high content validity and ensuring sensitivity to any changes associated with the programme.

The researcher had to decide how to group the items derived from the content of the AEWA programme for the measures and define the overarching constructs. It is recognised that the researcher could have grouped the items in different ways, which would have implications for the constructs commented upon in this study. How the concepts *'emotional well-being'* and *'potential challenges in adolescence'* have been operationalised in this study as a result of the researcher's interpretations and decision-making, may differ to how other researchers would interpret and use them. This has implications for how the results of this study are understood and for comparisons in relation to other research. For example, the AEWA programme focused upon sex and relationships, transitions and becoming independent as potential challenges in

adolescence, however, there may be other areas considered as a potential challenge.

8.4.5 Reliability

- *Bespoke measure*

A bespoke measure was developed for this study. To assess its reliability a Cronbach alpha coefficient was calculated to measure the internal consistency of the composite scores for each of the constructs it was designed to capture data for. The analysis discussed in section 4.3.4.3, illustrates the correlation coefficients calculated for two of the constructs captured in the measure are above 0.7, as deemed acceptable by George & Mallery (2003), however, two constructs fell very slightly below this level of acceptability. This may be due to the small sample of participants, which was below that recommended rather than the reliability of the construct.

It is acknowledged that the small sample use in the study, limits the conclusions that can be drawn from the Cronbach's alpha test on the test of internal items included in the scale. It is generally accepted that the larger the sample size, the more accurate the estimate of the Cronbach's alpha coefficient with a sample of 300 recommended by Kline (1986). However, it has been suggested by Yurdugül (2008) that a sample of n=30 is sufficient to gain a robust Cronbach's alpha score, if a large eigenvalue of above six is established through principle component analysis.

Although it was not possible in this study to secure a larger sample due to reasons explained in section 4.2.5, it is identified that further exploration of the reliability of the bespoke measure would be of benefit. For example, quality criteria by Terwee et al. (2007) identifies that the use of factor analysis along with Cronbach's Alpha should be used to assess whether items from a survey measure a single unitary concept. In order for a factor analysis to be completed on the bespoke measure a larger sample would be required of at least seven times the number of items, with a minimum of 100 subjects.

- Self-report measures

The use of self-report measures poses a risk to the validity of the findings of this study. It is known that in self-reporting, people often behave according to what they perceive to be expected from them (Camerini & Schulz, 2017), known in psychological research as demand characteristics, conformability or social desirability bias. Although McCambridge, de Bruin and Witton (2012) identified there are diverse definitions of what constitutes a demand characteristic, it has been argued that participants behave in accordance to what they perceive to be the purpose of a study (Goldstein, Rosnow, Goodstadt, & Suls, 1972). With this understanding, it is possible to conceive that although participants were not aware of the studies' research questions, they were aware that this study designed to evaluate the AEWA programme and this may have influenced their responses in the interview and self-report surveys. Participants may also have viewed their responses in the semi-structured interviews as an opportunity to secure further support, which could have accounted for the predominantly positive themes identified from the data collected.

Research suggests that participants display behaviours to support the experimental hypothesis (Nichols & Maner, 2008), such a bias in this study could potentially have obscured the real relationship between the independent variable, the AEWA programme and dependent variables, knowledge and confidence. Although, it is not possible to identify if such bias had an effect in this study and if so the magnitude of such effect a number of safeguards were in place, such as: encouraging participants to be open and honest about their experiences; triangulating different sources of information they provided; and ensuring participants were aware the information they provided would be confidential and anonymous.

- Intervention integrity

The AEWA programme has a clear structured and specified outcome, with the thematic analysis identifying that participants valued the structure and approach to delivery of the AEWA programme. Despite confirming fidelity to the intervention delivery, it is recognised that the presenters brought their own

experiences and approach to delivery. It is also acknowledged that participants were actively encouraged to engage in discussion and share their experiences, which may have also influenced the intervention effectiveness. The impact of these nuances on the intervention effects have not been explicitly explored in this study and may be viewed as a limitation. The use of thematic analysis did, however, illuminate some experiences that may have influenced the outcomes. For example, participants' valued sharing experiences, information and ideas with other parents of children with autism.

8.4.6 External Validity

- Sample

The minimum recommended sample of 21 participants per group in experimental designs (Onwuebgbuzie, Jiao & Bostick, 2004) was not secured for this research for reasons discussed in section 4.2.3, which is acknowledged as having implications limiting the generalisability of the findings of this study.

A significant risk to having a small sample is increased chance of making a Type I error by wrongly accepting the null hypothesis to be true when it is not, as it is harder to obtain statistical significance with a small sample (Hubbard & Lindsay, 2008). As indicated in the results in Chapter 5, all the results achieved statistical significance and the null hypotheses were rejected, so the small sample in this study did not have such a consequence in this study.

As identified in section 8.4.3, children with autism make up a heterogeneous group and it is therefore recognised that the population from which the sample was derived, was likely not representative of the wider population being investigated. All participants chose to attend and were proactive in self-referring to the programme. It is known that those in the most need of accessing support can often have difficulty accessing programmes aimed at parents. In this study, the participants were also self-selecting which also creates a bias impacting on the external validity of this study.

Data gathered for this study was from participants attending one AEWA programme and a control group. It is recognised that the contextual factors may

vary between programmes, influenced by participants and programme facilitators, which may have affected outcomes. The findings of this study are therefore context specific and are not intended to be generalised, but do however add to the body of knowledge.

In considering the limitations of the current study raised, the benefits of further research have been highlighted. Considerations for future research identified will be discussed in greater depth in the following section

8.5 Implications for Research

The AEWA programme has been developed in response to an identified need and is being used by a LA. This study it the first piece of research focused on evaluating the intervention, making the ecological validity of this study an identified strength. Future research would benefit from further evaluation of the programme, making adaptions to the methodological approach used in this study considering the limitations identified. Specifically, to support the generalisability of the current findings, future evaluative research on the AEWA programme should include gathering data from a greater number of participants from a broader number of programmes.

In building on from this study, further action to support the reliability and trustworthiness of the design should be taken. Additional investigation into the reliability of the bespoke measure used in this study is required with further modification as required. This could be done by using the measure in other AEWA programmes and statistically analysing the data captured. Going back to participants in the study to complete member checks of the researcher's interpretations of the qualitative data, to ensure it has been understood as intended, could also further enhance the trustworthiness of the qualitative design.

This study has provided an insight into the potential outcomes of the AEWA programme and highlighted fundamental aspects of the programme and secondary outcomes that are valued by participants attending the programme, along with considerations for development. Comparison investigations into the impact of alternative psychoeducation programmes and approaches to intervention delivery should be considered. For example, an investigation into the outcomes of intervention when delivered by the EPT compared to other professionals teams. Alternatively, comparison of the outcomes of the AEWA programme when delivered in a group setting when compared to the provision of information to individuals.

It has been acknowledged that this study has not explored the efficacy of the AEWA programme in achieving other outcomes that it is hoped the programme

would support. Exploration of outcomes relating to the emotional well-being of the children, young people and parents through experimental designs would be of benefit in future research to assess the cost benefit of rolling out the programme.

Alternatively, future studies may build directly on from the present study in the outcomes explored. It appeared the AEWA programme had a positive impact on participants' perceived knowledge and confidence. Based on these findings the following could be investigated: was this effect seen for those school staff attending with families; was this effect sustained if measures were repeated after 3-6 months; does an objective pre-post testing of knowledge support those reflected in participants' self-reports.

A theme coming out of the qualitative data was that the content of the programme was of relevance beyond parents of children with autism and the evidence that parents were sharing the knowledge they gained on the course wider, supported this. As indicated a consideration for future research would be the evaluation of the impact of the AEWA programme if adapted for use with participants who are not specifically parents of children with autism aged 8-13 years old. Future potential participants may include the child directly, parents with concerns about adolescence and the emotional well-being of their child and if delivered to school staff independent of families.

As discussed in the methodological evaluation (section 8.4), it has not been understood how the varying experiences brought by participants have influenced their experiences of attending the AEWA programme, their subsequent experiences and the outcomes as a result of attending. To overcome such limitations, future research could employ methods such as activity theory (Engeström, 1999) that allow for the study of interacting social systems when exploring intervention outcomes.

The current study indicated that the AEWA programme increases parents' perceived confidence. This study has not established a clear understanding of the causal and interacting mechanisms of how the programme has increased parents' confidence. A possible explanation is that the increased perceived

knowledge discussed in relation to research question one (section 8.3.1) or the validation from other parents (section 8.3.3.5) promoted participants' perceived confidence. Alternatively, the strategies identified to promote the emotional well-being were based on theoretically informed approaches, for example: cognitive-behavioural approaches and parents' application of such approaches to themselves instead of their children, could have potentially supported them to experience positive effects, such as increased confidence. A consideration for future research would be an exploration of the impact of possible interacting factors deriving from a parent programme that impacts upon confidence.

8.6 Implications for Practice

The results of this study need to be considered within the context of their limitations and that the AEWA programme would benefit from further evaluative research. However, it can be seen that the findings of this study potentially have different implications for stakeholders: the parent and their child with autism, the EPT and the LA policy makers. The implications at each of these levels will now be considered.

8.6.1 Implications for parents and children with autism

This study has provided evidence to support the efficacy of the use of a group psychoeducation programme as an approach to help parents meet the needs of their child with autism as they develop and challenges change. This is important considering stakeholders have called for research into interventions that help individuals with autism and their families manage the changing demands of daily life (Pellicano, Dinsmore & Charman, 2014).

8.6.2 Implications for Educational Psychologists

The outcomes identified in this study reflect the changes that can be potentially brought about in the development context of a child through a psychoeducation parent programme. This offers an approach to intervention that reflects many of the values held by EPs. Although this study has only focused on parents, the AEWA programme also accommodates the involvement of school staff demonstrating the approach provides an opportunity to share psychology and

evidence-informed approaches. This aligns with EPs views about the importance of working systemically to empower those in the developmental context of children and young people, to intervene to meet needs.

The AEWA programme was developed by EPs in response to a need identified in the EPT arising from psychological assessments of children and young people. Assessment is a core area of EPs' work to identify needs along with evidence-based approaches to intervention to support the needs including those specifically related to social, emotional and mental health as reflected in the Code of Practice (Department for Education, 2014). EPs are therefore well placed to signpost to the AEWA programme, when they identify an individual with autism for whom it may support. This study also highlights the potential role for EPs in being actively involved in developing efficacious approaches to intervention drawing on their knowledge of psychological theory and evidenced informed approaches to meet children and young peoples' needs where there are identified gaps in intervention.

The findings of this study have the potential to support the development of future similar programmes. It has highlighted aspects of the AEWA that may have supported the process of change for parents, which include the promotion of knowledge and confidence along with the opportunity for social connectedness as discussed in section 8.3.5. Elements of the programme that have supported the process of change should be considered in the development for future programmes. For example, the content supported the promotion of relevant and useful knowledge, while the delivery of the programme facilitated the opportunity for peer connectedness allowing for participants to connect with others to share of experiences, ideas and resources.

A challenge frequently faced by EPs that was raised in some of the themes from the study is the question of how EPs meet a broad range of needs through group interventions. Flexibility in the delivery of programme content is one approach to doing this. Where there is flexibility in curriculum-based programme, the use of instruments such as Target Monitoring Evaluation (Dunsmuir, Iyadurai, Brown & Monson, 2009) is a way in which EPs can encourage participants to

make explicit their needs to ensure they are responded to appropriately. Another alternative is an approach to group intervention known as Adaptive Coaching (Bridge, Ashton-Jones & McLean, 2018), which has been developed by a team of EPs. Instead of being guided by a curriculum this approach to intervention offers a flexible approach, in which EPs respond to the needs of the group as they arise in discussion drawing on the professional knowledge base in psychology.

It is recognised that EPs work with a wider socio-political context (Fallon, Woods and Rooney, 2010). In the LA where the AEWA programme was developed, the EPT is moving towards a partially traded service with work being commissioned or determined by broader LA policy and priorities. The EPT need to consider how they can support the roll-out of the AEWA programme as a commissioned service. As identified within the study, there is the wider relevance of the programme beyond parents. For example, EPs work closely with a range of professionals such as those from schools, teams within the LA and external commissioned services all whom respond to social and emotional needs, social communication needs, parenting needs and challenging behaviour. It is therefore identified that there are possible opportunities to explore with other potential stakeholders as to if and how the AEWA programme could be delivered in its current or an adapted form.

It is recognised that the priority given to EPs being involved in the delivery of psychoeducation programmes is affected by the challenges faced by EPT and the need to balance demands. There are a number of vacancies in the EP profession and recruitment has been recognised as a challenge (National College for Teaching and Leadership, 2014). This, along with the increasing number of Education, Health and Care plans being issued (Department for Education, 2017), which EPs are required to provide statutory advices to the LA for, impacts on time available for such activities.

Considering the demands on EPs time, it is worth noting that the curriculum approach to intervention lends itself to being delivered by an appropriately trained individual. This raises the question of whether the same outcomes could

be achieved by an individual outside the EPT, which would require further investigation. Asgary-Eden & Lee (2011) suggests EPs take a role in developing the understanding and mastery of the skills needed to deliver the parent programme as opposed to being involved in direct delivery.

8.6.3 Implications for Local Authority and Policy

From an Ecological Systems Theory perspective (Bronfenbrenner, 1979), it is known that economic and political systems influence the context of a child's development. Policy is known to influence parents' behaviour to achieve positive outcomes for children, through the use of interventions for parents (Social Mobility Commission, 2017). In the context of this study, it is recognised that the LA and broader policy have influence over the on-going implementation of the AEWA programme and other psychoeducation interventions.

At a time of austerity, when local authority budgets are stretched there is a need for accountability in prioritising public spending. Given the associated cost of delivering psychoeducation interventions for parents, policy decision-makers may question "if" such programmes should be delivered by the LA and if so "how". Nevertheless, the personal cost to the individual and their family along with the financial cost of not intervening should not be underestimated, as highlighted in the review of literature in Chapter 2. This provides a strong argument for preventative early intervention that resonates with the researcher.

It is important that policy ensures limited resources are used for evidence-based intervention focused where they will be most effective, ensuring they meet the needs of the most vulnerable. This study has suggested the AEWA programme is one approach to intervention that should continue to be considered by the LA, although it is acknowledged research would benefit from some further evaluative investigation into the programme and attention given to some of the practical considerations raised throughout this discussion.

Chapter 9 - CONCLUSION

9.1 Original contribution of this research

Parent programmes are a well-established approach to intervention to promote better outcomes for children and parents (Barlow et al., 2010; Barlow et al., 2012; Bennett et al., 2013) and have been well used to support families with children with autism (Forehand et al., 2013). As highlighted in the review of research in section 2.6, there has been very little research into the parent programmes as an approach to intervention to support the emotional well-being of children and young people with autism, specifically as they approach adolescence with the new potential challenges they face. The primary aim of this study was to build on from previous research and make an original contribution by evaluating the Autism, Emotional Well-being and Adolescence (AEWA) programme, with a secondary aim of considering more broadly the use of psychoeducation parent programmes as an approach to intervention to support children and young people with autism through adolescence.

This study is unique in that it is the first piece of research to study the AEWA programme, a locally developed psychoeducation programme used by an EPT in a LA. It has used a mixed method approach enabling the researcher to explore quantifiable changes, along with participants' experience to give a holistic view of the effectiveness of the AEWA programme.

9.2 The Autism, Emotional Well-being and Adolescence programme as an efficacious approach to intervention

The findings suggest it can be seen as an effective approach to intervention to achieve outcomes for parents, which includes increasing their perceived knowledge and confidence in supporting the emotional well-being of their child with autism, particularly through the potential challenges of adolescence. It also appears the AEWA programme has the potential to positively influence other outcomes for some parents, including: their thinking in how they support their child and how they view their capacity as a parent; the promotion of positive

feelings; and increasing their knowledge and capacity to implement the strategies they have learnt.

This study has also provided an insight into the valued experiences of attending the AEWA programme: First, the content of the programme was reflected upon positively. Second, the opportunity the AEWA programme afforded participants to come together with other parents of children with autism was valued by participants. Finally, it was identified that the structure and approach to delivery used in the AEWA programme was appreciated.

Considering the findings of this study discussed along with the best available research, it appears that parent programmes are an appropriate and effective approach to intervention to support the changing needs of children and young people with autism as they approach adolescence, having the potential to have a positive influence on outcomes for parents and children.

As discussed in the methodological evaluation there are a number of limitations identified with the design approaches used in this study, particularly those linked to the inference quality, the reliability and generalisability of the findings in this study. The positive findings discussed do warrant further research into the AEWA programme and more broadly the use of psychoeducation interventions as an approach to support children and young people with autism and their families through adolescence.

9.3 Concluding summary

In summary, the evidence from the study suggests that a psychoeducation programme aimed at parents of 8-13 year olds of children with autism focusing on emotional well-being and adolescence can have positive effects on parents. Such effects include changing parents' thinking, feelings and behaviour all of which have the potential to change the developmental context of the child. Although this study has not provided evidence of the wider impact on child outcomes, previous research highlights the potential for such parent outcomes to positively impact on outcomes for children and as suggested warrants further investigation.

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APPENDICES

Appendix A: Ethical Approval Letter

The University of Nottingham
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SJ
Ref: S956

Wednesday, 05 April 2017

Dear Neil Ryrie and Tracey Bishop,

Ethics Committee Review

Thank you for submitting an account of your proposed research 'An Evaluation Of The Autism, Emotional Well-Being And The Teenage Years, A Locally Developed Psycho-Education Programme For Parents Of Children With Autism Spectrum Disorder'.

That proposal has now been reviewed by the Ethics Committee and I am pleased to tell you that your submission has met with the committee's approval.

Final responsibility for ethical conduct of your research rests with you or your supervisor. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society and the University Research Ethics Committee. If you have any concerns whatever during the conduct of your research then you should consult those Codes of Practice. The Committee should be informed immediately should any participant complaints or adverse events arise during the study.

Independently of the Ethics Committee procedures, supervisors also have responsibilities for the risk assessment of projects as detailed in the safety pages of the University web site. Ethics Committee approval does not alter, replace, or remove those responsibilities, nor does it certify that they have been met.

Yours sincerely

Professor Stephen Jackson
Chair, Ethics Committee

Appendix B: Example of information sheet given to participants (experimental group)

School of Psychology

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

An evaluation of the Autism, Emotional Well-being and adolescence programme for famillies, a locally developed psycho-education programme for parents of children with autism spectrum disorder.

Ethics reference S956

Researcher(s): Tracey Bishop lpxtb2@nottingham.ac.uk

Supervisor: Neil Ryrie lpanr@exmail.nottingham.ac.uk

Thank you for agreeing to take part in the evaluation research into the Autism, Emotional Well-being and Adolescence programme for families, a locally developed psycho-education programme for parents of children with autism spectrum disorder. Before participating it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

Evaluating the Autism, Emotional Well-being and Adolescence programme for families is important. The information gathered can help develop a better understanding of the impact of the programme for participants. It is also hoped the evaluation will provide an understanding of people's experiences when they attend the programme. This information can then be used to continue to develop the programme in the future and to ensure the programme is a positive experience for those who attend.

The evaluation is made up of three parts:

- Identifying personal targets that you hope the Autism, Emotional Well-being and Adolescence programme for families will help with. This will be done in a short meeting with me, the researcher, before the start of the programme. The meeting will last no more than 15 minutes. The targets will be then be revisited at the end of the programme.
- Completing a short questionnaire before the start of the programme and at the end of the programme.
- An informal interview after you complete the programme. You will be invited to answer a few questions about your experience attending the programme. You will also be invited to share whether or not you have made any changes, as a result of attending the programme.

Participation in the research is entirely voluntarily. Attending the programme does not commit you to being involved in the evaluation research. Your invite to attend the programme is regardless of whether you decide to participate in the research or not.

Please be assured that, if you commit to being involved in the research, all the information you provide will be kept confidential and used for research purposes only. All results will be kept anonymous and you will not be identifiable in the write up of the results.

If you experience any emotional distress as a result of taking part in the research, or feel you need additional support, advice or guidance, a list of relevant support agencies within the local area has been provided at the end of this information sheet. You are also able to contact the Educational Psychologists facilitating the Autism, Emotional Well-being and Adolescence programme for families.

If you have any questions or concerns please don't hesitate to raise them. We can also be contacted after your participation at the above email address.

If you have any complaints about the study, please contact:
Stephen Jackson (Chair of Ethics Committee)
stephen.jackson@nottingham.ac.uk

Adult support services

Young Minds Parent Helpline - free and confidential support for anyone worried about the emotional problems or behaviour of a child or young person.
Website: www.youngminds.org.uk/for_parents
Telephone: 0808 802 5544

Lincolnshire Relate - Provide support with family life and parenting
Website: www.relate.org.uk
Telephone: 0300 003 2164
Email: enquiries@relate.org.uk

PAACT (Parents and Autistic Children Together) Advise, information and support to parents/carers of children and young people who have been diagnosed with an Autistic Spectrum Disorder.
Website: www.paact.org.uk/
Telephone: Gordon Forsyth 07935 222963
Email: paactsupport@hotmail.co.uk

Appendix C: Example of initial contact letter providing an overview of the research and an invitation to participate

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

19 May 2017

Dear Parent

My name is Tracey Bishop and I work for XXXXX as a Trainee Educational Psychologist. I am completing my training at the University of Nottingham and as part of this training I am required to undertake supervised research.

My chosen research is an evaluation of the Autism, Emotional Well-being and Adolescence Programme. I am writing to invite you to take part in the research evaluating this programme, as a parent who will be attending it.

Evaluating the Autism, Emotional Well-being and Adolescence Programme is important. The information gathered can help develop a better understanding of the impact of the programme for participants. It is also hoped the evaluation will provide an understanding of peoples' experiences when they attend the programme. This information can then be used to continue to develop the programme in the future and to ensure the programme is a positive experience for those who attend.

The evaluation is made up of three parts. You will be invited to participate in some or all aspects of the evaluation, which are detailed below:

- Identifying personal targets that you hope the Autism, Emotional Well-being and Adolescence Programme will help with. This will be done in a short meeting with me, the researcher, before the start of the programme. The meeting will last no more than 15 minutes. The targets will then be revisited at the end of the programme.
- Completion of a short questionnaire at two time points.
- An informal interview after you complete the programme. You will be invited to answer a few questions about your experience attending the programme. You will also be invited to share whether or not you have made any changes, as a result of attending the programme.

Participation in the research is entirely voluntarily. Attending the programme does not commit you to being involved in the evaluation research. Your invite to attend the programme is regardless of whether you decide to participate in the research or not.

Please be assured that if you commit to being involved in the research, all the information you provide will be kept confidential and used for research purposes only. All results will be kept anonymous and you will not be identifiable in the write up of the results.

If you would like to be involved and agree to participate, please be aware that you can withdraw at any time, without providing a reason.

I do hope you feel able to help in the evaluation of the Autism, Emotional Well-being and Adolescence Programme.

Please indicate on the reply slip below whether or not you are happy to be contacted by the researcher prior to the start of the programme and return in the enclosed pre-paid envelope. Alternatively, you can email xxxxx the programme administrator, making your preference known by **Tuesday 30 May**.

Yours sincerely

Tracey Bishop
Doctoral Researcher and Trainee Educational Psychologist

✂.....

Reply slip

Name ……

☐ I would like to be involved in the research evaluating the Autism, Emotional Well-being and Adolescence Programme

☐ I **do not** wish to participate in the research evaluation of the Autism, Emotional Well-being and Adolescence Programme

☐ I would like some more information about the research before I make a decision about participating or not and I am happy to be contacted by the researcher.

Please return in the pre-paid envelope enclosed by **Tuesday 30 May**

Appendix D: Consent Form

School of Psychology

Consent Form

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

An evaluation of the Autism, Emotional Well-being and Adolescence programme for families, a locally developed psycho-education programme for parents of children with autism spectrum disorder

Ethics Approval Number: S956

Researcher: Tracey Bishop lpxtb2@nottingham.ac.uk

Supervisor: Neil Ryrie lpanr@exmail.nottingham.ac.uk

The participant should answer these questions independently:

- Have you read and understood the Information Sheet? YES/NO
- Have you had the opportunity to ask questions about the study? YES/NO
- Have all your questions been answered satisfactorily? YES/NO
- Do you understand that you are free to withdraw from the study? (at any time and without giving a reason) YES/NO
- I give permission for my data from this study to be shared with other researchers provided that my anonymity is completely protected. YES/NO
- Do you agree to take part in the study? YES/NO

"This study has been explained to me to my satisfaction, and I agree to take part. I understand that I am free to withdraw at any time."

Signature of the Participant: **Date:**

Name (in block capitals)

I have explained the study to the above participant and he/she has agreed to take part.

Signature of researcher: **Date:**

Appendix E: Measure developed to evaluate the Autism Emotional Well-being and Autism Programme (T1).

Name: _____

(Please note your name will be removed immediately after the data collection and you will be assigned an anonymous code before any data analysis).

This questionnaire seeks to capture your concerns, knowledge and confidence when considering emotional well-being of your child with Autistic Spectrum Disorder.

It is not uncommon for parents at some time to worry about any aspect of their child's development. Please read through the list of statements and indicate which statement best reflects your view. (Please circle only one answer for each statement that best reflects you.)

My child's level of anxiety *How worried, nervous, or uneasy they feel.*	Hardly ever worries me	Worries me a little	Worries me a lot
My child's resilience *How able they are to recover from difficulties.*	Hardly ever worries me	Worries me a little	Worries me a lot
My child's self-esteem *Their confidence in their own worth or abilities*	Hardly ever worries me	Worries me a little	Worries me a lot

Knowledge

People display different levels of knowledge in promoting children and young people's emotional well-being. **Considering your child with ASD**, please indicate whether you agree or disagree with each statement below. Please circle the number that best represents your views. You are asked to choose only one number from 1 to 5, with 1 being 'strongly disagree' with the statement and 5 being 'strongly agree' with the statement.

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
I have a good understanding of…					
1. What anxiety is	1	2	3	4	5
2. Factors that can lower resilience in my child	1	2	3	4	5
3. What might help my child's awareness of appropriate sexual behavior	1	2	3	4	5
4. How to help my child to cope when faced with difficulties	1	2	3	4	5
5. Approaches to reduce my child's anxiety levels	1	2	3	4	5
6. The challenges my child may face with sex and relationships in adolescence	1	2	3	4	5
7. How to increase resilience in my child	1	2	3	4	5
8. What self-esteem is	1	2	3	4	5
9. How to solve problems at home	1	2	3	4	5
10. The links between thoughts, feelings and behaviour	1	2	3	4	5
11. The impact of ASD on my child's self esteem	1	2	3	4	5
12. Approaches to promote resilience in my child	1	2	3	4	5
13. Approaches to help my child recognise and label their emotions	1	2	3	4	5
14. The relationship between anxiety and anger in my child	1	2	3	4	5
15. What resilience is	1	2	3	4	5
16. Approaches to promote self esteem	1	2	3	4	5
17. The challenges my child may face in adolescence	1	2	3	4	5
18. The impact of anxiety upon my child	1	2	3	4	5
19. How to develop my child's awareness of appropriate relationships to keep them safe	1	2	3	4	5
20. The associations between ASD and anxiety	1	2	3	4	5
21. Significant transitions (life changes) my child faces in adolescence	1	2	3	4	5
22. Approaches to support the transitions my child faces	1	2	3	4	5

Confidence

People display different levels of confidence in their ability to promote children and young people's emotional well-being. Considering your child with ASD, please indicate whether you agree or disagree with each statement below. Please circle the number that best represents your views. You are asked to choose only one number from 1 to 5, with 1 being 'strongly disagree' with the statement and 5 being 'strongly agree' with the statement.

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
I am confident I can …					
1. Recognise when my child is anxious	1	2	3	4	5
2. Increase my child's resilience	1	2	3	4	5
3. Help my child think more positively to support changes in their feelings and behaviours	1	2	3	4	5
4. Increase my child's self esteem	1	2	3	4	5
5. Develop my child's independence	1	2	3	4	5
6. Increase my own resilience	1	2	3	4	5
7. Help my child develop an understanding of appropriate relationships in adolescence to keep them safe	1	2	3	4	5
8. Help my child to recognise and label their emotions	1	2	3	4	5
9. Support my child's transitions (life changes)	1	2	3	4	5
10. Help my child to develop coping strategies	1	2	3	4	5
11. Help my child develop an understanding of appropriate sexual behaviour in adolescence	1	2	3	4	5
12. Reduce my child's anxiety	1	2	3	4	5
13. Reduce my child's anger	1	2	3	4	5
14. Share information to support my child's transitions	1	2	3	4	5
15. Problem solve at home during difficult times	1	2	3	4	5

Finally to help classify your answers to help with the analysis and interpretation, please answer the follow personal data questions.

Please provide the following details about your child with ASD

Age : _____ Gender Female □ Male □

Diagnosis:_____ Approximate age of diagnosis _____

or Stage of Diagnosis_____

Number of older siblings: _____ Ages: _____

Number of younger siblings:_____ Ages: _____

Please provide the following details about <u>you</u>

Gender: F □ M □

Age: 18-29 years old □ 30-49 years old □
50-64 years old □ 65 years and over □

Relationship to the above child: Mother □ Father □
Other please describe _____

Number of children:_____

Employment status: Full-time □ Part-time □ Unemployed □
Student □ Retired □

Highest level of education: None □
GCSE / Level 2 equivalent □
A-level / Level 3 equivalent □
First Degree □
Postgraduate □

How supported do you feel in parenting your child?

None	Low	Moderate	High	Very High
1	2	3	4	5

Other than the Autism, Emotional Well-being and Adolescence programme what interventions have you or your child accessed since your child received their diagnosis of ASD? (Please tick to indicate)

	Current Involvement	**Previous Involvement**
Psychological education		
Social groups		
Autism Outreach		
School Staff		
Educational Psychology		
Clinical Psychology		
Medical		
Speech and Language Therapists		
Occupational therapy		
Physiotherapy		
CAMHS		
Social Care		
Other Professionals		
Charities		

Appendix F: Intervention Fidelity Checklist

Intervention fidelity review

Completed by _____ Date _____

Phase of the intervention:

Delivered by:

Materials provided:

Activities:

Was the intervention modified? Please describe the changes (what, why, when, and how)

Any other relevant information.

Intervention fidelity checklist

Content	***Delivered***
Introduction to the programme	
Module 1	
Aims and objectives	
Explanation of what anxiety is	
How to recognise anxiety	
Links between anxiety and autism	
Links between anxiety and anger	
The anger cycle	
The low arousal approach to reduce anger	
Module 2	
Introduction to Cognitive-Behavioural principles to promote wellbeing / reduce anxiety.	
Recognising and labeling emotions	
Linking feelings and behaviour	
Changing unhelpful thoughts	
Approaches to problem solving	
Module 3	
Explanation of resilience is	
Risk factors and resilience	
Protective factors and resilience	
Building resilience	
Explanation of self-esteem	
How ASD can potentially impact on self-esteem	
Ways to support the development of self-esteem	
Developing coping strategies	
Approaches to problem solving	
Identification of relaxation techniques	
Emotional wellbeing strategies in school	
Signposting resources to support emotional wellbeing	
Module 4	
The links between adult and child wellbeing	

Responses to challenging behaviour	
The importance of "me time"	
Revisiting the link between thoughts and feelings	
Role models	
Feeling good through helping others	
Support networks	
Connecting with others	
Mindfulness approaches to support wellbeing	
Module 5	
The potential impact of anxiety and stress in making relationships difficult.	
How to support needs in adolescence, at a time of change	
Typical development of sex and relationships in adolescence	
Consideration of the potential challenges in the development of sex and relationships for adolescents with ASD	
Consideration of what needs to be taught to support the development of positive relationships	
An overview on how to educate young people with ASD about sex and relationships	
Developing an understanding of the difference between a 'good' and 'bad' physical contact	
Teaching appropriate sexual behaviour	
Identifying what needs to be considered to support young people to stay safe in adolescence	
Module 6	
Developing an understanding of the term transition	
Identification of times transitions	
Details of the 'Five Dimensions of Inclusion'	
Overview of the Mental Capacity Act (2005)	
Overview of Person Centred Planning and how it can be used to support transition	
Details of different planning tools to support Person Centred Planning	
Developing independence	
Celebrating success	

Appendix G: Inter-rater Intervention Fidelity Agreement Calculation

	FACILIATOR'S LOG			RESAERCHER'S OBSERVATION		
	DELIVERED	DELIVERED WITH DEVIATION	DELIVERED	DELIVERED WITH DEVIATION	AGREEMENT	DISAGREEMENT
Introduction to the programme	X		X		X	
Module 1						
Aims and objectives	X		X		X	
Explanation of what anxiety is	X		X		X	
How to recognise anxiety	X		X		X	
Links between anxiety and autism	X		X		X	
Links between anxiety and anger	X		X		X	
The anger cycle	X		X		X	
The low arousal approach to reduce anger	X		X		X	
Module 2						
Introduction to Cognitive-Behavioural principles to promote wellbeing / reduce anxiety.	X		X		X	
Recognising and labeling emotions	X		X		X	
Linking feelings and behaviour	X		X		X	
Changing unhelpful thoughts	X		X		X	
Approaches to problem solving		X		X	X	
Module 3						
Explanation of resilience is	X					
Risk factors and resilience	X					
Protective factors and resilience	X					
Building resilience	X					
Explanation of self-esteem	X					
How ASD can potentially impact on self-esteem	X					
Ways to support the development of self-esteem	X					
Developing coping strategies	X					
Identification of relaxation techniques	X					
Emotional wellbeing strategies in school	X					
Signposting resources to support emotional wellbeing	X					

Module 4						
The links between adult and child wellbeing	X		X		X	
Responses to challenging behaviour	X		X		X	
The importance of "me time"	X		X		X	
Revisiting the link between thoughts and feelings	X		X		X	
Role models	X		X		X	
Feeling good through helping others	X		X		X	
Support networks	X		X		X	
Connecting with others	X		X		X	
Mindfulness approaches to support wellbeing	X		X		X	
Module 5						
The potential impact of anxiety and stress in making relationships difficult.	X		X		X	
How to support needs in adolescence, at a time of change	X		X		X	
Typical development of sex and relationships in adolescence	X		X		X	
Consideration of the potential challenges in the development of sex and relationships for adolescents with ASD	X		X		X	
Consideration of what needs to be taught to support the development of positive relationships	X		X		X	
An overview on how to educate young people with ASD about sex and relationships	X		X		X	
Developing an understanding of the difference between a 'good' and 'bad' physical contact	X		X		X	
Teaching appropriate sexual behaviour	X		X		X	
Identifying what needs to be considered to support young people to stay safe in adolescence	X		X		X	

Module 6						
Developing an understanding of the term transition	X		X		X	
Identification of times transitions	X		X		X	
Details of the 'Five Dimensions of Inclusion'	X		X		X	
Overview of the Mental Capacity Act (2005)	X		X		X	
Overview of Person Centred Planning and how it can be used to support transition	X		X		X	
Details of different planning tools to support Person Centred Planning	X		X		X	
Developing independence	X		X		X	
Celebrating success	X		X		X	
				TOTAL	***39***	**0**
				PERCENTAGE AGREEMENT	***100***	

Appendix H: Groups of items to address constructs with Cronbach Alpha scores.

Understanding

- **Construct - Emotional Well-being**

I have a good understanding of…

U_1 What anxiety is

U_2 Factors that can lower resilience in my child

U_4 How to help my child to cope when faced with difficulties

U_5 Approaches to reduce my child's anxiety levels

U_7 How to increase resilience in my child

U_8 What self-esteem is

U_9 How to solve problems at home

U_10 The links between thoughts, feelings and behaviour

U_11 The impact of ASD on my child's self esteem

U_12 Approaches to promote resilience in my child

U_13 Approaches to help my child recognise and label their emotions

U_14 The relationship between anxiety and anger in my child

U_15 What resilience is

U_16 Approaches to promote self esteem

U_18 The impact of anxiety upon my child

U_20 The associations between ASD and anxiety

Cronbach's Alpha T1= 8.59 / Standardized 8.60 n=16 factors

Cronbach's Alpha T2 = 9.46 / standardized 9.45 n-16 factors

Cronbach's Alpha for combined

T1 & T2 = 0.934/ Standardized 0.933 n=32 items

- **Construct - Challenges in Adolescence**

I have a good understanding of…

U_3 What might help my child's awareness of appropriate sexual behaviour

U_6 The challenges my child may face with sex and relationships in adolescence

U_17 The challenges my child may face in adolescence

U_19 How to develop my child's awareness of appropriate relationships to keep them safe

U_21 Significant transitions (life changes) my child faces in adolescence

U_22 Approaches to support the transitions my child faces

Cronbach's Alpha T1= 0.698 / Standardized 0.693 n=6 factors

Cronbach's Alpha T2 = 0.949 / Standardized 0.95 n=6 factors

Cronbach's Alpha for combined

T1 & T2 = 0.851/ Standardized0.836 n=12 items

<u>Confidence</u>

- **Construct - Emotional well-being**

I am confident I can …

C_1 Recognise when my child is anxious

C_2 Increase my child's resilience

C_3 Help my child think more positively to support changes in their feelings and behaviours

C_4 Increase my child's self esteem

C_8 Help my child to recognise and label their emotions

C_10 Help my child to develop coping strategies

C_13 Reduce my child's anger

C_15 Problem solve at home during difficult times

Cronbach's Alpha T1= 0.817 / Standardized0.806 n= 7 Items

Cronbach's Alpha T2 = 0.917/ standardized 0.912 n= 7 Items

Cronbach's Alpha for combined

T1 & T2 = 0.882/ Standardized 0.882 n=14 items

- **Construct - Challenges in Adolescence**

I am confident I can …

- C_5 Develop my child's independence
- C_7 Help my child develop an understanding of appropriate relationships in adolescence to keep them safe
- C_9 Support my child's transitions (life changes)
- C_11 Help my child develop an understanding of appropriate sexual behaviour in adolescence
- C_14 Share information to support my child's transitions

Cronbach's Alpha T1= 0.672 / Standardized 0.679 n=5 Items

Cronbach's Alpha T2 = 0.855 / Standardized 0.848 n= 5 Items

Cronbach's Alpha for combined

T1 & T2 = 0.785/ Standardized 0.772 n=10 items

Appendix I: Questions asked when piloting the questionnaire developed for evaluating the Autism, Emotional Well-being and Adolescence programme.

The questionnaire attached has been developed as a tool to evaluate a parenting programme developed for families with children with ASD. It is hope through piloting the questionnaire before it is used with the programme, feedback can be gained to ensure it is fit for use.

Thank you so much for agreeing to take the time to complete the questionnaire and for answering the questions below. Your reactions, comments and suggestions are all of interest and will be used to develop the questionnaire.

Questionnaire Feedback

How long did it take you to complete the questionnaire?_____

Please indicate how understandable was the language used in the questionnaire?

Very Easy Easy Medium Hard Very Hard

Please highlights any wording on the questionnaire that you feel should be developed to make it easier to understand.

_____ _____
_____

Please indicate how clear the instructions were for completing the questionnaire?

Very Clear Clear Medium Unclear Very Unclear

Please highlight any instructions you feel need to be clarified on the questionnaire.

_____ __
_____ _____

Do you have any suggestions regarding the addition or deletion of any questions?

_____ __
_____ __

Do you have any suggestions regarding improving the format of the questionnaire?

_____
_____

Please add any additional comments or suggestions about the questionnaire you may have. (Please include any concerns you have about the questionnaire).

_____
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Thank you for your feedback.

Appendix J: Adapted personal data questions for survey template **to** evaluate the Autism Emotional Well-being and Adolescence Programme (T2).

Finally, to help classify your answers to help with the analysis and interpretation, please answer the follow personal data questions. If any changes in your knowledge or confidence are observed, this information will help identify whether they can be attributed to any other source of intervention or support.

How supported do you feel in parenting your child?

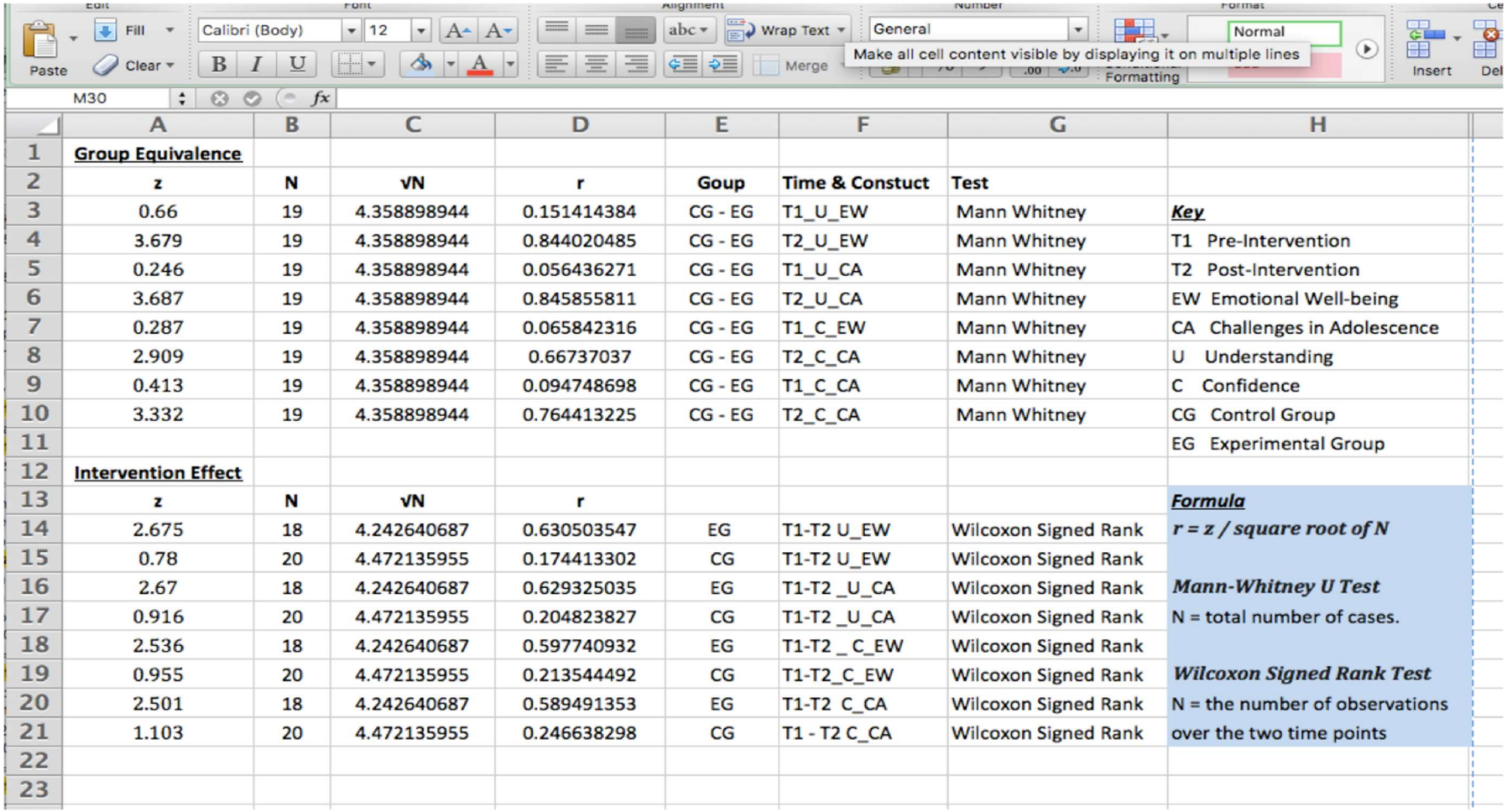
None	Low	Moderate	High	Very High
1	2	3	4	5

Have you or your child received any other interventions or support, linked to your child's diagnosis of ASD since **6th June 2017** when you started attending the Autism, Emotional Wellbeing and Adolescence programme? (Please tick to indicate)

	New Involvement	**Continuation of existing involvement**
Psychological education		
Social groups		
Autism Outreach		
School Staff		
Educational Psychology		
Clinical Psychology		
Medical		
Speech and Language Therapists		
Occupational therapy		
Physiotherapy		
CAMHS		
Social Care		
Other Professionals		
Charities		

If you have indicated that you have received other interventions or support since **6th June 2017**, please provide brief details in the box below:

Appendix K: Effect Size



	A	B	C	D	E	F	G	H
1	**Group Equivalence**							
2	**z**	**N**	**√N**	**r**	**Goup**	**Time & Constuct**	**Test**	
3	0.66	19	4.358898944	0.151414384	CG - EG	T1_U_EW	Mann Whitney	***Key***
4	3.679	19	4.358898944	0.844020485	CG - EG	T2_U_EW	Mann Whitney	T1 Pre-Intervention
5	0.246	19	4.358898944	0.056436271	CG - EG	T1_U_CA	Mann Whitney	T2 Post-Intervention
6	3.687	19	4.358898944	0.845855811	CG - EG	T2_U_CA	Mann Whitney	EW Emotional Well-being
7	0.287	19	4.358898944	0.065842316	CG - EG	T1_C_EW	Mann Whitney	CA Challenges in Adolescence
8	2.909	19	4.358898944	0.66737037	CG - EG	T2_C_CA	Mann Whitney	U Understanding
9	0.413	19	4.358898944	0.094748698	CG - EG	T1_C_CA	Mann Whitney	C Confidence
10	3.332	19	4.358898944	0.764413225	CG - EG	T2_C_CA	Mann Whitney	CG Control Group
11								EG Experimental Group
12	**Intervention Effect**							
13	**z**	**N**	**√N**	**r**				***Formula***
14	2.675	18	4.242640687	0.630503547	EG	T1-T2 U_EW	Wilcoxon Signed Rank	***r = z / square root of N***
15	0.78	20	4.472135955	0.174413302	CG	T1-T2 U_EW	Wilcoxon Signed Rank	
16	2.67	18	4.242640687	0.629325035	EG	T1-T2 _U_CA	Wilcoxon Signed Rank	***Mann-Whitney U Test***
17	0.916	20	4.472135955	0.204823827	CG	T1-T2 _U_CA	Wilcoxon Signed Rank	N = total number of cases.
18	2.536	18	4.242640687	0.597740932	EG	T1-T2 _ C_EW	Wilcoxon Signed Rank	
19	0.955	20	4.472135955	0.213544492	CG	T1-T2_C_EW	Wilcoxon Signed Rank	***Wilcoxon Signed Rank Test***
20	2.501	18	4.242640687	0.589491353	EG	T1-T2 C_CA	Wilcoxon Signed Rank	N = the number of observations
21	1.103	20	4.472135955	0.246638298	CG	T1 - T2 C_CA	Wilcoxon Signed Rank	over the two time points
22								
23								

Appendix L: Interview Protocol

Go back through Participant Information Sheet, revisit confidentiality statement and confirm Informed consent

Introductory script

Thank you for meeting with me today as part of research evaluating the Autism, Emotional Well-Being and the Adolescent programme, that you have recently attended.

I am aware that you have already provided some information to support the evaluation on a questionnaire, however, this interview is about exploring your views of the course and any impact you feel it has had since completing it.

You are not obliged to answer all the questions, so if there is a question you do not feel comfortable answering, please indicate that you would like to move on. Please feel free to stop the interview at anytime to take a break or end it.

As previously identified all information will be kept confidential and used for research purposes only. All data collected will be stored in compliance with the Data Protection Act. In reporting the findings of the evaluation you will not be identifiable.

Do you have any questions before we get started?

Interview questions

Could you tell me about yourself?

- Experiences around ASD?
- What support you have?

Could you tell me about x's and their needs?

- Does x have a diagnosis of ASD?
    - When did they receive it?
    - What stage of the diagnosis are they at?
    - How did the diagnosis come about?
    - What was / is you experience of the diagnosis process?
    - What has been your experience of support linked to x's diagnosis / impending diagnosis
- What are x's strengths and difficulties?

Could you tell me about what brought you to the Autism, Emotional Well-being and Adolescence programme?

Could you tell me you experiences of attending the Autism, Emotional Well-being and Adolescence programme?

- What worked well on the programme?
- What makes you think that worked well?
- What areas could have been improved?
- How do you think this could have been done?
- Is there anything you would like to have had more of?
- Is there anything you would like to have had less of? What makes you think this? Do you think the programme met your needs?

Do you think since attending the programme you have implemented any changes as a result of attending the programme?

- Changes linked to supporting x's emotional well-being
- Changes linked to planning for transition?
- Changes linked to preparing x's for the Teenage years?
- Why

What kind of strategies and resources are you personally able to use to support x's emotional well-being?

- What strategies do you know about?
- What strategies do you actually use? Why ?
- What strategies do you feel confident with? Why?

Have you been able to use any of the strategies and resources personally to support your own emotional well-being?

- What strategies do you know about? Why
- What strategies do you actually use? Why
- What strategies do you feel confident with?

How well do you think you are able to meet x's emotional well-being needs?

- What kinds of things make you think that?
- To what extent do you think you should be able to meet x's needs

How well do you think you are able to support x's transitions in the adolescence?

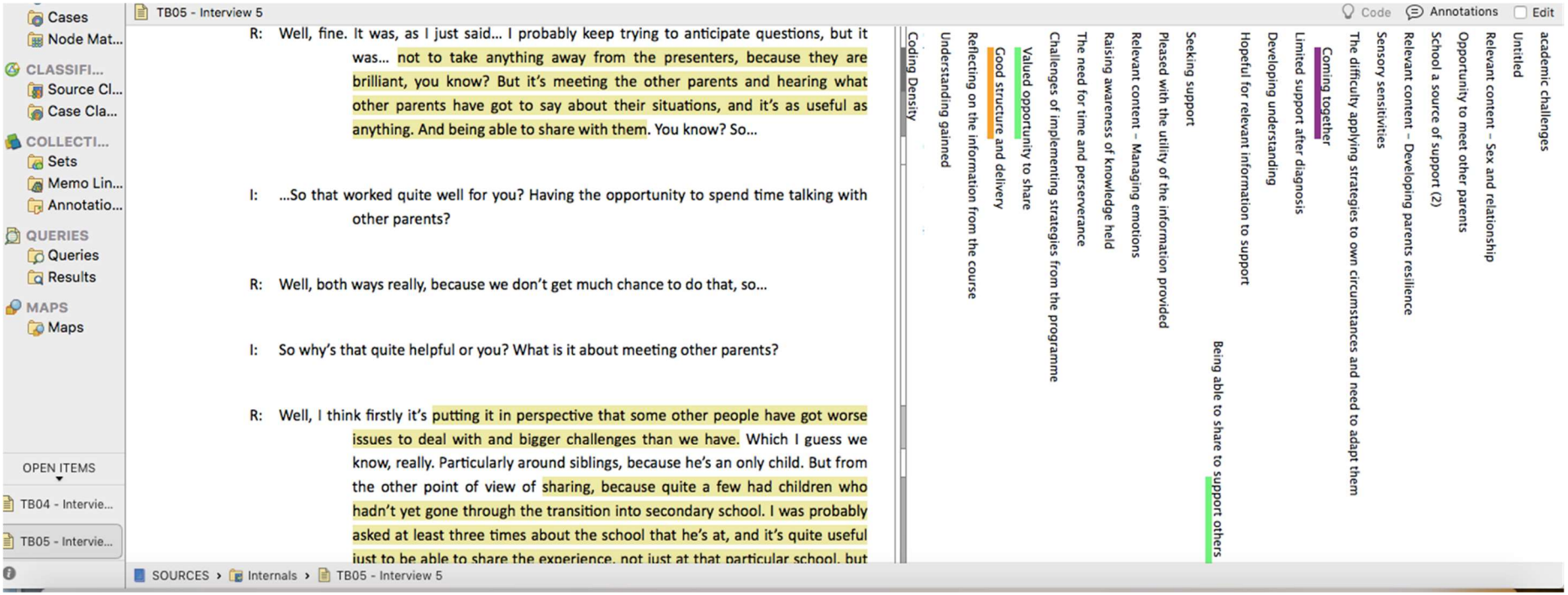
- What kinds of things make you think that?
- To what extent do you think you should be able to meet x's needs in transition?

Is there anything you would like to add to help in the evaluation of the Autism, Emotional Well-being and Adolescence programme?

Debrief

Thank you so much for taking the time to participate in this study. As previously identified, after I have analysed all the results of the study, I will provide feedback in a written summary of the overall research findings. It is anticipated that this will be completed in May 2018.

Appendix M: Example of part of a coded transcript



Appendix N: Tables identifying initial codes generated from transcript and how they relate to the identified themes and sub-themes

Initial codes to themes and sub-themes relating to the research question about participants' reflections of their experience of attending the AEWA programme

Initial Codes	***Sub-themes***	**Themes**
More on PDA More on transitions More on building resilience in the adults around the child More depth More on promoting independence More on consideration how to adapt strategies More input on PDA approaches	*Desire for greater depth of knowledge and strategies to support to have been provided in the programme*	***Areas for developing the AEWA programme***
Relevance of AEWA programme to	*Offering the programme to a*	

children without autism Relevance of AEWA programme to school children Relevance of AEWA programme for teachers	*wider range of people due to the relevance and applicability of the content for a wider range of individuals*	
Improve by gaining child's voice		
Improve by managing an individual in the group		
Challenge of making it applicable to all		
Consider accessibility of course		
Developing understanding	*Developing understanding*	***Learning through attending the AEWA programme***
Raising awareness of knowledge already held	*Raising awareness of knowledge already held*	
Gaining knowledge of strategies	*Gaining knowledge of strategies*	
Accessible content Positive school professionals attend		***Good structure of the AEWA and approach to delivery***

Valued activities included Valued the programme being facilitated by EPs Valued of opportunity to share knowledge and experiences as part of the course		
Pleased with the relevance – Developing independence Pleased with the relevance – Developing parents' resilience Pleased with the relevance- Managing emotions Pleased with the relevance – Promoting resilience Pleased with the relevance - Sex and relationships Pleased with the relevance - Transition Pleased with the relevance	*Pleased with the relevance of the modules of content*	***Satisfaction with the content of the AEWA programme***
Pleased with the utility of the content Interesting content	*Pleased with the utility of the content*	

Positive affirming experience		***Positive experience attending the AEWA programme***
Positive experience attending the AEWA programme		
Feeling accepted by coming together		***Valued coming together with other parents of child with autism***
Sharing information and ideas with others to support	*Sharing information and ideas*	
Connecting with people with shared experiences	*Valued connecting with people with shared experiences*	
Provided perspective		

Initial codes to themes and sub-themes relating to the research question about what are participants' subsequent experiences as a result of attending the AEWA programme?

Initial Codes	**Sub-themes**	**Themes**
The difficulty applying strategies to own circumstances and need to adapt them	The difficulty applying strategies to own circumstances and need to adapt them	**Challenges of implementing strategies from the programme**
The need for time and perseverance	The need for time and perseverance	
Not responding to strategies		
Implementing strategies		**Change in behaviour**
Starting conversations		
Increased confidence		**Experienced a positive effect on their affect**
Empowering		
Reducing parents anxiety		
Sharing course information with others		**Sharing course information with others**
Clarity in thinking Feeling more prepared	Developing participants' awareness of their capacity to respond to their child's needs	**The knowledge and understanding gained on the AEWA programme**

Reflecting on course information		**influenced thinking**
Following the programme sustained increased awareness	Following the programme sustained increased awareness	

Appendix O: Tables illustrating data for each themes and sub-themes

Illustrative examples of the themes and subthemes relating to participants' experience of the AEWA programme

Participants experience of the AEWA programme	Areas for consideration to develop the AEWA programme	TB03 - Interview 3 1. I think the beginning of the course would have been right for me then because when the children are younger you can start to think and put these strategies in place, as in how to help them. (…) I was thinking I wish I'd done that earlier... Yes, I definitely think being on that course would have been better for me when XXXX was about 6 or 7. She's 10 now. TB06_-_Interview_6 2. If I could have said that thing with the bottle maybe two or three years ago XXX would have understood that a lot better 3. It's the same issue, is that while it's great to hear everybody's point of view I think often some people are allowed to indulge in that and then it gets so that it's not of benefit to the group. (…)That happened a little bit on that where one or two people started to make it very personal and it didn't apply to anybody else. 4. (…) my husband can't access these because he's at work (…) it should be able to be accessed by people who work because they're sharing the same difficulties aren't they. 5. I was writing all this down and even if it didn't apply to XXXX I was thinking "I know someone that could apply to".	
		Offering the programme to a wider range of people due to the relevance and applicability of the content for a wider	TB03 - Interview 3 6. I: So you think maybe some of the aspects of it has got a broader application R: Yes I think everybody. It will touch upon everybody in their day-to-day. Nobody runs like clockwork do they? There is always something that will happen that the course, somebody could find something from that course in their day-to-day life that would be

		range of individuals	beneficial. 7. What I would love to see happen (…) is that you can go into schools and chat to children. If there was something that you could do, a similar thing, break it down for children and talk to children in general about it, (…) something more that you're skills are in, just to talk to children in general and say "if you're ever feeling anxious" and give them tips on coping strategies, relaxation in your classroom, something like that. 8. I can't understand why people would not do something like that knowing what I feel I came out with and knowing what you know as professionals, I can't understand why people wouldn't think that was not a good thing. I: So you thought maybe more work around the transitions and emotional wellbeing. R: Yes. I: But for schools. R: Yes. TB04 - Interview 4 9. I think all the teachers (…) I think they should all be made to go on courses like this, so they do get it.(…) these practices should be shared. 10. If you gave teachers the same course that I've just been on, and the EarlyBirds one, it would give them a complete understanding of what they're dealing with TB05 - Interview 5 11. I'm gathering they're intending to run it in another part of the county. I hope they will continue to run it so that other people around XXXX can get the benefit, TB01 - Interview 6 12. I picked up things that I could talk to XXX about as well, never mind that I went there specifically for XXXX, often these courses you find out things that apply to all children don't you? And you see in all children. So even though you were there for autism specifically it's really good that you can, you think "actually that applies to a neurotypical".

		Desire for greater depth of knowledge and strategies to support to have been provided in the programme	TB01 - Interview 1 13. I: Are there any areas that you think could have been improved? R: The only area, it was only a very minor thing, and it's pretty much down to time constraints really, was the last day it seemed a bit compressed. 14. More on the transitions, I think. And I think the building resilience in adults because I imagine, the impression that one gets is that the medical profession, in particular, don't appreciate… 15. I: So you feel like some more around resilience, around the adults would have been quite useful because of the demand. R: Because of, yes, yes, definitely. And particularly with the anger and aggression, and whatnot, because we have to cope with it. 16. … so although it would be nice to see more PDA stuff in there (…) So maybe, yes, maybe a little bit more about that…. TB02 - Interview 2 17. It's always hard to be able to come home and use them [strategies](…) examples of different ways you could adapt things 18. also some ideas of how to be… "Yeah, okay, I'm still feeling really crap right now, but how do I deal with him at that time as well?" TB03 - Interview 3 19. we just skimmed over everything and actually we could have gone into things a bit more in-depth … 20. I: Is there anything you'd have to have spent a bit more time exploring? R: … more because it's coming up to XXXX's time of life when she's getting older so it's more like dealing with things in the teenage years. It's how to deal with that as a parent, how to cope with the things that you're going to face so it was more towards the end of the course when we talked about children growing up really, what they're going to experience and how they're going to be. For them it's coping with the day-to-day

		aspects of getting older. 21. It was only touching upon [transition] I think. Perhaps they could have done a little bit more in-depth with that… I don't know what else you could have said but maybe we could have done a little bit more about [transition]. TB05 - Interview 5 22. In the last week, I think, there was a bit about promoting independence … but specifically promoting more independence and being able to cope on their own, and I think that was… that could have been brought out a bit more(…) Yes, I think it did. At the same time, they could have possibly filled it out a bit more.
Good structure of the AEWA and approach to delivery		TB01 - Interview 1 23. I think the whole thing was really well structured 24. Some of the activities were quite nice as well (…) I like the bear cards. TB03 - Interview 3 25. I thought it all worked really well. It all really went smoothly on your part and I found it really interesting, 26. I think it's really great that they [school staff] get the opportunity to come as well… 27. I think the balance is right because we shared quite a lot of information but then we had breaks which gives you time to digest it, have a bit of a breather and then come back to it. TB04 - Interview 4 28. It's nice that teaching assistants come, and teachers (…) that they're taking the time to understand their children.

	TB05 - Interview 5 29. not to take anything away from the presenters, because they are brilliant (…) and being able to share with them 30. going through a group discussion or everyone on the table's going through exercises, as to well, how would you approach this kind of issue 31. I: Is there anything else that you think worked quite well on the programme? R: Well, yes, most of it really. It's just a matter of in what way it's useful. Again, when you're going through a group discussion or everyone on the table's going through exercises, as to well, how would you approach this kind of issue? And just being a bit clearer about what some of the things are. TB06_-_Interview_6 32. I thought that it was delivered in a very down to earth easy to understand way. I took quite a lot from the two ladies that were delivering it, yes. 33. …[The Breakwell Cycle] it's something visual I can understand easily and it's something I can take away 34. just think there's a different perspective to be tapped into and all the practical experience that the lady said they deliver to schools (…)you've got a different sort of specialisms and bringing all that together is just fantastic. It's worth goodness knows how much in money terms, a fortune, but it's brilliant, absolutely brilliant.
Positive experience attending the course	TB03 - Interview 3 35. I really enjoyed it. I have to say I loved it. (…) It didn't disappoint me at all. I just really enjoyed being there and listening to what people had to say (…) It was really positive and I'd love to do another one. (…) I really enjoyed everything. 36. It did and you made us feel so welcome and at ease straight away which is so important and

		obviously everyone else felt like that because people were talking all the time. 37. I haven't been out for ages so it was almost exciting to hear other people talking and getting excited about what you were saying and thinking "yes actually this has happened to me" and "we need help with this" so yes it was good. It was really good. 38. I think the whole experience was so worth it and because I thought can't believe I'm doing this, the free sort of thing, just sitting there, you felt like you were having a chat with friends, coffee morning sort of thing and you came away and it was a bit of a relief as a parent, 39. I feel there was nothing negative at all. It was all really positive. TB04 - Interview 4 40. I enjoyed the programme. 41. It's the first course I've ever been on that they go, there's you, you need time for you, you need to understand that you're a person as well as a mum and a dad and a carer and all the rest of it. So that was quite nice, to recognise that. 42. R: And then you don't feel like an outcast there. (…) Yes, I did feel safe. TB05 - Interview 5 43. I think it has been very good. I think it's definitely needed, and you know,
	Positive affirming experience	TB01 - Interview 1 44. As I say, the very fact that PDA was even mentioned was a huge plus, the very fact that it was mentioned, acknowledged. It's a real thing, it does cause problems, and you're not on your own kind of thing. TB02 - Interview 2 45. I think it made me think as well that actually I do know stuff and that I'm probably doing ok and yes things are difficult but I'm trying my best and that's all I can really do. 46. it's helped a lot with that actually. Because a lot of the things that I think of, I thought… that I thought… or even some of the things that I might have started to try already when you're being told, actually this is a good

			thing to do. It's like, oh okay, and it validates what you might have thought already TB04 - Interview 4 47. It was nice to feel appreciated, it was nice to feel that you are doing a good job. Being a parent is a hard enough job, but being a parent to one autistic kid is hard. 48. made me realise that no, I wasn't contradicting my methods and my beliefs by doing that. 49. R:I did… listening to other autistic mums that do do things, and I think oh, well, they're doing it, maybe it is okay. I: So a bit of permission, maybe. a. R: Yes, because that's what you feel like.
	Gaining knowledge to raise awareness, develop understanding and knowledge of how to respond to needs	TB02 - Interview 2 50. It's given me loads of different things to think about. TB04 - Interview 4 51. So that's something I've learnt as well – it might not necessarily be something that's happened there and then, it could be a memory that's made them remember it and they've come up with it. 52. So now I've seen that, and the fact that the kids get their input in it is very good as well. That's something I wouldn't have known before. If I hadn't gone on the course, I'd have just been sat there with no knowledge. Now I have knowledge of how it works, what the kids' input is TB06_-_Interview_6 53. I took quite a lot from the two ladies that were delivering it,	
		Gaining knowledge of strategies	TB01 - Interview 1 54. Do you remember on the last day you had that one page profile from a…? (…)we're going to try and work with the school to try and get something a bit more like that going. (…) It was just XXXX to a T really.

			TB02 - Interview 2 55. I really like the blob tree things as well so I think that will be really good to look at with him. 56. Understanding (…) and how to deal with it TB03 - Interview 3 57. I found it really interesting, things I didn't know about at all, when we did the Breakwell cycle, all those little strategies and things like that to help. TB04 - Interview 4 58. (…) you saying right, well, this is the time for that, this is the time for that. Put them in boxes, and learn how to deal with it, and then just switch off and move on instead of making a huge deal out of it (…) So that was quite good to learn. 59. Is it people profiles, they call them? And how the child wrote it out herself, and how she wanted to be seen, and things like that. That I found very, very good TB05 - Interview 5 60. But just to get some sort of confirmation (…) and how you can support him is very helpful. TB06_-_Interview_6 61. I think some of the tips that they gave out were really really good. 62. I think just being given these little tips and little pointers, like what I found very useful
		Developing understanding	TB01 - Interview 1 63. R: It was the iceberg thing and all of that (…) Because it really does just demonstrate how much is going on underneath. TB03 - Interview 3 64. Like I said I realising that what might seem the norm for us as adults and your own childhood experience. (…) it is just again being more mindful (…) That isn't how everybody works.

			TB04 - Interview 4 65. Understanding that what they're going through is normal… 66. You know, learning that my reaction towards them was probably the wrong reaction, (…) because then they were feeding off it. So that was quite good to learn. TB05 - Interview 5 67. And just being a bit clearer about what some of the things are. (…) I think, well, resilience: I thought I knew what it was(…) but when I thought about it, I thought I don't really understand what it is, and still asked what I could do to help him. (…) But just to get some sort of confirmation as to what exactly we're talking about 68. Well just, as I said, helping to clarify what I need to know and how I can help him, because we do feel a bit on our own a lot of the time. TB05 - Interview 6 69. …[The Breakwell Cycle] it's something visual I can understand easily and it's something I can take away and visually show my older boy and my husband
		Raising awareness of previous knowledge	TB01 - Interview 1 70. Although I knew it already it really brought it home how much the anxiety really sits at the core of everything, and everything spins out from there (…) I think that was really the biggest take home message was deal with the anxiety and the other things will start to deal with themselves to a certain degree. TB02 - Interview 2 71. But I suppose being reminded just to look after yourself is always good, because I think you do forget, TB04 - Interview 4 72. [referring to developing social understanding of appropriate places for

			sexualised behaviour] You kind of know techniques, but these courses kind of jog… it's sat back in the back of your head, but it brings it to the forefront of yes TB05 - Interview 5 73. But it does make you realise that there's a continual challenge as a parent, especially as they're just getting into their teens, about teaching the whole sort of emotional changes as well as the physical changes that they're going through. 74. I'm even more aware now of what I probably knew before, that other people have been telling me, is that I need 'me time' as well. TB06_-_Interview_6 75. So it's brought it more to the front a bit, that that's actually quite important for the wellbeing of the family isn't it?
	Pleased with the content of the AEWA programme		TB03 - Interview 3 76. Because it was all so interesting… 77. I found it really interesting, things I didn't know about at all, when we did the Breakwell cycle, TB04 - Interview 4 78. Is there anything you found particularly interesting or useful? R: I think learning the stress levels 79. I think it was pretty thorough, generally. TB05 - Interview 5 80. I think it has been very good. I think it's definitely needed, and you know, 81. I think it was pretty thorough, generally. 82. I think some of the tips that they gave out were really really good. TB06_-_Interview_6 83. thought it was really useful 84. I think some of the tips that they gave out were really really good. 85. Yes. That [the Breakwell Cycle] is so interesting because, again, it's something visual I can

	understand 86. The relaxation techniques that we learned are good, are really good for everybody I think.	
	Pleased with the relevance of content	TB01 - Interview 1 87. I was actually very pleasantly surprised about how much there was about PDA. 88. it's all very linked up with his anxiety, and whatnot. And that was the other part of the course that was good, it was the transitions bit, well, the anxiety bit and the transitions bit. 89. I: Are there any of those modules that you feel were particularly useful for you? R: The transitions was because, as I say, there's the transition into year six, and then there's the transition into… TB02 - Interview 2 90. …It has, it's given me loads of different things to think about. 91. I really like the blob tree things as well so I think that will be really good to look at with him. 92. when I was on the course I was like, I need to do this, I need to do that, I need to do that. TB03 - Interview 3 93. (transition)... Really relevant, absolutely. It's major. That's probably one of the most… things in anybody's life is going from primary school to secondary school. Just the day-to-day transitions and things that you were talking about. It makes you aware of actually it's not just this, it's doing the small things that you do. TB04 - Interview 4 94. It's the first course I've ever been on that they go, there's you, you need time for you, you need to understand that you're a person as well as a mum and a dad and a carer and all the rest of it. So that was quite nice,

			to recognise that(…) It was nice that you said, no, go and do something for you. I was like, what do you mean, do something for me? TB05 - Interview 5 95. Well again, these things [emotional wellbeing and adolescence] are highly relevant when he's this age (…) it's all highly relevant. 96. I think, the first session on anxiety etc., all very relevant, (...) So that wasn't completely new but it still… it was very relevant. And the fact that it's not completely new, I still find myself having to think, 'hang on a minute; I've got to manage this situation' in the spur of the moment. 97. yes, taking things one step at a time, is definitely… in terms of problem solving, is definitely relevant to him.
		Pleased with the utility of the information provided	TB01 - Interview 1 98. I: So what was it about that strategy that you thought was useful? R: It was just XXXX to a T really. A lot of the techniques and things that you would use for, I don't know, high functioning ASD don't really work for PDA. And it was nice to see… TB02 - Interview 2 99. I think it was all really helpful to be honest. I found it all really… there wasn't anything in particular that I thought I don't really get why they're doing that or… it was just, it was good TB03 - Interview 3 100. I found it really interesting, things I didn't know about at all, when we did the Breakwell Cycle, all those little strategies and things like that to help 101. What was beneficial was when we did touch on resilience in adults because you need to have your time. TB04 - Interview 4 - 102. I think with any course, you have to take out… No course is ever going to be 100% you. You have to pick out the bits that work for you,

			and then leave the other bits that don't work for you, but the bits that work for you are invaluable. 103. I: Is there anything that you found particularly useful for you out of the areas that we covered? R: The one thing I did find was the inappropriate and appropriate times, and things like that. That's one thing I really struggle with, my two don't care where they are, they will just randomly come out with something… 104. I: Was there anything else that was particularly relevant for you? R: Understanding that, like I said, the transition is for normal children as well as autistic children was very good, and different techniques for the stress. TB05 - Interview 5 105. I think, well, resilience: I thought I knew what it was, and I certainly knew it was important, it was one of those sort of things we latched on to as a word soon after he became… after he was diagnosed, but when I thought about it, I thought I don't really understand what it is, and still asked what I could do to help him. So to some extent, I'm still processing all that. But just to get some sort of confirmation as to what exactly we're talking about and how you can support him is very helpful. 106. I…any modules that you found particularly relevant or useful for you? R: Well, yes, as I say, that, I think, in particular. The stuff… some of the things in the third week to do with sex education and internet safety. TB06_-_Interview_6 107. It covered things that were new to me like the mindfulness. That was really really good. Some of the things in there, what do they call it? I've forgotten what they call it, where they turn a negative thought around into a positive. 108. I: It's a part of the reframing. R: That's it, yes. All of that I found dead useful.

			109. I think just being given these little tips and little pointers, like what I found very useful was that chart where you're coping with things in small bite size pieces rather than tackling a great big issue all at once. 110. I found it really useful and valuable, yes, and it is good that it's delivered by Ed Psychs
	Valued coming together with other parents	111. I think the whole experience was so worth it (…) you felt like you were having a chat with friends, coffee morning sort of thing and you came away and it was a bit of a relief as a parent,	
		Connecting with people with shared experiences	Interview 2 112. just knowing that you're not the only one going through something is kind of really helpful I think. 113. it's always really good to listen and talk to other people that are in the same boat as you, that's definitely really helpful Interview 3 114. I was just really looking forward to meeting new people, meeting parents with similar situations. It didn't disappoint me at all. 115. it's invaluable to know about other people's experiences because you know you're not the only one in the situation that you are… 116. …it was really lovely just to know that there are people out there in a similar situation(…) I came away knowing that there are other people out there going through it. Interview 4 – 117. …to see other people that are going through that as well, that really does help, that you don't feel like an outcast. (…)You feel as if you can open

			up and talk because you're not an outcast, because everybody else is in the same boat as you, (…) came to the group, and everybody's been through that, experienced it and understands what it's like to be the outcast. And then you don't feel like an outcast there. 118. that's a massive impact for me. Listening to how different people deal with it, TB06 - Interview 6 119. a sense of camaraderie as well and you're not on your own because you can feel very lonely with this as well 120. what you're describing to them about your child's behaviour is just not a shock. It's just "oh yes we have that similar thing at home". 121. So yes it can feel a bit lonely so doing that sort of thing as well just to know that there are other people who are either up at night or having a similar experience in Tesco. It is comforting
		Sharing experiences, information and ideas	Interview 3 122. I just really enjoyed being there and listening to what people had to say and if there was anything new I could take from it to bring home so yes, 123. Also when everybody shared websites and books that you can use, that was really good because I didn't know half of that was out there. 124. I remember one mum saying on the course that actually they've got to start making their own choices sometimes. So that was the idea. I do mother her too much. Interview 4 125. …like the girl that was sat next to me told me about PACTT… I'd never heard about them. Do you know what I mean? Different things like

			that, that was good, TB05 - Interview 5 126. …But it's meeting the other parents and hearing what other parents have got to say about their situations, and it's as useful as anything. And being able to share with them 127. the contact with the parents. As much as anything, sharing ideas as to, 'well, we've done this with our autistic child' or 'we've taken them there'. So, yes. 128. going through a group discussion or everyone on the table's going through exercises, as to well, how would you approach this kind of issue? And just being a bit clearer about what some of the things are. 129. I: Is there anything else that you think worked quite well on the programme? R: Well, yes, most of it really. It's just a matter of in what way it's useful. Again, when you're going through a group discussion or everyone on the table's going through exercises, as to well, how would you approach this kind of issue. TB06_-_Interview_6 130. It's always handy hearing other people's stories, their personal stories and what's worked for them and what hasn't. That is always useful. 131. sometimes they've approached it differently and it's been really good as well. You think "I'm going to try that". So yes. Really good.

Experience since attending the AEWA programme.	**Challenges of implementing strategies from the programme**	TB04 - Interview 4 1. …but the behaviour and the anxiety, I still struggle with. I put everything in place that people tell me to do, but my two just don't respond to it.	
		The need for time and perseverance	TB01 - Interview 1 2. It's early days. (…)So to actually get him to sit down and do breathing exercises, or whatever it is, would be quite a struggle in the beginning (…) I: are there any that some you think you will be able to implement? R: I think with perseverance, yes, … 3. …I pick one thing, I'll do that for a little while and then go back to it and do something else. TB03 - Interview 3 4. I think it's possibly a bit early to say. I think it's always going to be a long process. TB05 - Interview 5 5. there's not been a lot of time to… really I would like to follow up some leads I got at the time anyway 6. …Yes, well, that's in principle. In doesn't necessarily work in practice in the time I'm there, but it's certainly something to bear in mind for the summer holidays.
		The difficulty of applying strategies to own circumstances and the need	TB01 - Interview 1 1. I don't think he'd take well to the old pizza massage, he's not particularly touchy-feely. I mean, he is, but again it's on his terms. That's the whole thing, everything is on his terms. 2. And the problem with his anxiety is whatever you try to do to deal with it, the old PDA kicks in and it's like, "Yes, I'm not doing that," or

		to adapt them	whatever. TB02 - Interview 2 3. … different strategies and things. It's always hard to be able to come home and use them, especially with XXXX, you kind of have to maybe think a little bit outside the box and adapt it a little bit to suit him a bit better. 4. Like the CBT based thinking and I kind of had a chat with XXXX about it and he was like, I don't like the red and green words, I really don't like those. And I was like, well choose a colour or… it doesn't have to be… or give it a name or whatever. But he really didn't like the idea at all. So I kind of like just left the name thing. But when he started saying things I kind of tried to put them round in a different way. So I've tried doing that and very, very occasionally he'll be like, okay, and he'll take it, but it's very rare. But I don't know, I'm trying to persist with it a little bit. 5. So again, it's just kind of adapting it to suit him at little. TB04 - Interview 4 6. Some of the things they were saying on the course, I was thinking, well, I can kind of see a bit of that, but that isn't how it plays out. 7. With the techniques they were saying right, you know, the pizza massage – you get halfway through it, they just go, oh, I don't want this. 8. So it was kind of difficult to put some of the techniques in place, because obviously each child is individual. 9. I found some of it really, really helpful to use, but other things [strategies], I thought that wouldn't work for mine. 10. The problem I found with that is some of them don't like you touching them, and a lot of the techniques were touching, so I found that quite difficult to do because it's like, why are you doing…

		11. So I tried to do the pizza massage, and she was like, what are you doing? So I did try different things, and she went oh, what are you doing, yes.
Change in behaviour	TB05 - Interview 5 12. I think so, because that's something, which my wife and I have been talking about a bit, even since we got back from the course, (…) we need to move him on and just give him little challenges that promotes his independence a bit. (…) I: Okay. So were you having those conversations before the course, or is that something…? R: Not really, no. It has been more since, I think.	
	Implementing strategies	TB02 - Interview 2 13. Like the CBT based thinking (…) So I've tried doing that and very, very occasionally he'll be like, okay, and he'll take it, but it's very rare. But I don't know, I'm trying to persist with it a little bit. 14. I think trying to get XXXX to label his emotions, because at the minute he's either happy or he's angry and those are his two… he doesn't have anything in between, so just to try and teach him… there was quite a few different ways that we went through, just to go through trying to get him to label how he's feeling. So I've tried to be a bit more "I'm feeling like this because…" 15. I've got all of my little notes and stuff but I pick one thing, I'll do that [strategy] for a little while and then go back to it and do something else. TB03- Interview 3 16. I took from the whole course to be more mindful (…) I'm trying to

			think “hang on a minute, I did the course, I’m going to try to do this differently to how I did it before. (…) Instead of snapping or getting a bit cross try to just be calm 17. I’ve used it on my son actually and it’s doing the massaging and it’s trying to talk to him, what he’s saying has been quite negative so trying to turn it around. (…) Trying to get him to think differently. 18. the massage, I loved it. We all loved the massage one and I did show him (…) so I’ve tried to say to him to do the finger pressure points, 19. With XXXX I definitely feel happier with her. Every day she’ll say she’s not getting in the shower (…) I haven’t got cross since and that is because I’m thinking yes she’ll get in that shower eventually, I’ve just got to wait for it. (…) Yes but do you know what? The result of that is she takes herself off and puts the shower on herself now. So maybe that is because I’m not rising to her getting silly. I couldn’t believe it. Last week I was thinking is that the shower going? And it’s XXXX and she’s singing, she’s got in it. TB04 - Interview 4 20. …it was nice for you to say, right, go and do something. And the thing was, I didn’t know what to do. When you said go away and have some ‘me’ time, it was like… Oh, dear, what do I do? (…) I rode my horse, which I hadn’t done in two years, so I did do that, which was nice. 21. Because I will now say, that’s not the time or the place. 22. The other thing I did learn from the course was (…) little rewards along the way, rather than having to wait for the big reward at the end, because they’ll lose momentum waiting to get to the big one. So I have started doing little things like that. 23. One thing I did do was sit and talk to them about what they would

		like to do, instead of me always being the person in charge asking them what activities they'd like to do. (…)I also said to XXX, what could we do to help XXX in the morning? How could we do things to improve his behaviour and get him out on time? So I asked for her input in that, as well. So involving them. TB06_-_Interview_6 24. I think I can be overcritical when things go wrong so I've tried to pull back with both of them and try to be more positive in ways to help them. I don't think I was very very negative with them but I think that definitely could have improved. 25. I've tried to just take a breath and think about it rather than react too much. 26. I: You mentioned the green thoughts. R: Yes. I: Have you tried that? R: I have, yes, I have, with both of them. 27. I: The problem-solving ? R: Yes. I find I can apply that to both of them. So that's been useful, not in a formal way, I've not been writing it down but I have it in my mind.
Sharing course information with others	TB01 - Interview 1 28. We've actually taken a close look at that [one-page profile], and (…) we're going to try and work with the school to try and get something a bit more like that going. (…). Because although they don't see a great deal of resistance at school, it is there it's just they're not looking deep enough for it… TB03 - Interview 3 29. …so I've tried to say to him to do the finger pressure points, you can just sit there and	

you can just press your fingers. Hopefully…
I: You're using the strategies within the family rather than just with XXXX.
R: Yes. I actually did go through the Breakwell Cycle and to tell him what he experiences is quite normal, it's trying to normalise things because he thinks he's the only one. He's very… the walls are up at the moment and he thinks it's just him experiencing it and going through it. So I was trying to say that we all do this.
I: So it's not just sharing strategies, it's some of the information…
R: Yes because I feel XXXX can understand it. He's just that little bit older. It did work actually. He did say "right, okay" so him knowing that there's other people other there.

30. I've talked about it with people at school because they were really interested. It's amazing actually to see how many people are really interested in what I was doing because the children are of similar age and they've got older or younger siblings and they're going through a tough time. So I said we've talked about this. So sharing that information from the course.

TB06_-_Interview_6

31. …my husband is a secondary school teacher and a lot of the stuff I came back with he was feverishly writing it down and taking notes so that he could take it back to his school and share it there.
32. I remember she shook the bottle (…) That has just stuck with me completely and my husband has spoken about that back in his school as well because it's very difficult to get through to somebody. Autism is not very visible is it? So it's very difficult to get through to somebody how XXXX can look like he's had a good day but then why is he behaving so badly in the evening?
33. picking things up [explanations from the course] like that, is just brilliant to talk to somebody else about, to help them understand what it's like for XXXX.
34. …it's something visual I can understand easily and it's something I can take away and visually show my older boy and my husband…
35. I will often get an email or someone will ask me "can I put you in touch with this

	parent?" And I've got almost like a folder of hard copy knowledge, it's not just my experience, there is the science behind it if you like. 36. I've been able to better explain maybe why XXXX behaves like that and get my older son and my husband involved in a bit of a discussion about it as well.
The knowledge and understanding gained on AEWA course is influencing thinking.	TB01 - Interview 1 37. Breathing I think would be very good, anything to get him to relax (…) 38. R: I think we came to the conclusion that he really needs to meet her [his next teacher] in small doses to begin with, ease that transition step by step. Yes, problem solving step by step, like we said, little bits. 39. R: It was quite refreshing to hear that that is not actually not strictly true [you should not use cognitive behavioural approaches]. (…) I: Did you think you might, would you try to use those? R: Certainly give it a try, yes, yes. I went as far as to read a few papers that have been done actually, the big meta-analysis of CBT in autistic kids … TB02 - Interview 2 40. I think I'm trying to think a lot more about what's behind behaviours and stuff like that and as some people said on the course, it's not necessarily, what happened today, yesterday, last week. 41. I think some of those things that we did, like the cards and stuff like that, we might look into. TB03 - Interview 3 42. I do things, I do stop and think oh, yes, the lady said that, and do this, and… So I do reflect back on what I learnt over the three weeks. 43. I'm trying to think "hang on a minute, I did the course, I'm going to try to do this differently to how I did it before". 44. I do think it's from trying to be more mindful of being… just thinking sometimes there's no point arguing or saying anything (…) because I am more mindful from being on the course …

		TB04 - Interview 4 45. it's made me stop beating myself up so much that I'm this rubbish mum that doesn't cope. 46. It did, it made me think that yes, there was little rewards… They might not have been major, but yes I am allowed to give them. Because I'd gotten to the stage where I thought, right, they can't have rewards because their behaviour's shocking. 47. Yes. I got that from the course, because I never thought about that. 48. So I do get the I need to look after myself thing now, and do little things for myself that make me happy so that I'm in a better place for them. So I do understand that now. TB05 - Interview 5 49. I think so, because that's something [promoting independence] which my wife and I have been talking about a bit, even since we got back from the course, (…) He's more comfortable sometimes, especially in a busy to just do what he did yesterday, but actually, we need to move him on and just give him little challenges that promotes his independence a bit. 50. And just being a bit clearer about what some of the things are. 51. I think there are definitely changes in our way on thinking about things that he does… he not only needs time to himself, which we know, but he needs time when we can actually indulge him in doing things he wants to do to relax him a bit.	
		Following the programme increased awareness	TB01 - Interview 1 52. Although I knew it already it really brought it home how much the anxiety really sits at the core of everything, and everything spins out from there. TB03 - Interview 3 53. I took from the whole course to be more mindful because you can get into this rut where you're just repeating the same mistakes every day so to have that refreshed in the mind again is really

			useful TB05 - Interview 5 54. I'm even more aware now of what I probably knew before, that other people have been telling me, is that I need 'me time' as well. (…) it has made me think that I need time when I'm not under pressure, and I can just do things that I enjoy doing.
		Developing awareness of capacity to respond to their child's needs	TB01 - Interview 1 55. Certainly I'm far more adamant that he needs to meet his teacher and break down those barriers. TB02 - Interview 2 56. I think it made me think as well that actually I do know stuff and that I'm probably doing ok and yes things are difficult but I'm trying my best and that's all I can really do. 57. I kind of feel a little bit more prepared as well, as to who I can talk to or what kind of things I might be able to suggest that might be helpful and stuff 58. Things like the one-page profile examples and the different advice on where you could go for information and stuff. I think it's given me a bit of a, ok so this is what I could do, rather than thinking I don't know what I'm going to when he gets to that kind of… yeah it makes you feel a little bit better because I know I've got to do something now rather than just completely unknown. 59. R: Yes, I feel a little bit more like I can say the right thing or know where to go to for information and stuff. I: And is that because of the course or is that… R: Yes, that's definitely helped a lot. 60. …made me realise that no, I wasn't contradicting my methods and my beliefs by doing that. TB03 - Interview 3 61. I'm trying to think "hang on a minute, I did the course, I'm going to

		try to do this differently to how I did it before". TB04 - Interview 4 62. made me realise that no, I wasn't contradicting my methods and my beliefs by doing that. TB06_-_Interview_6 63. I do feel a bit more prepared but I feel better for XXX as well 64. I feel like I'm waiting. I've got this action plan that I'm ready to... 65. …knowing that I've got a bit more knowledge, a few more tips, whereas before it was like if I'm asked this question or if this certain thing arises what am I going to do? … 66. I feel like I'm waiting. I've got this action plan that I'm ready to...
Positive effect on affect	TB02 - Interview 2 67. I think it made me think as well that actually I do know stuff and that I'm probably doing ok (…) Kind of made me feel a bit better in that way I suppose as well. 68. I kind of feel a little bit more prepared as well, as to who I can talk to or what kind of things I might be able to suggest that might be helpful and stuff TB06_-_Interview_6 69. …things like puberty, adolescence, they're not really on his radar yet which is good because I feel better having done that first (the course) rather than him going through it and me trying to catch up 70. I do feel a bit more prepared but I feel better for XXX as well 71. I feel a lot less frightened. 72. …I felt a little bit calmer knowing that I've got a bit more knowledge, a few more tips, whereas before it was like if I'm asked this question or if this certain thing arises what am I going to do? I was getting a bit blank, a bit kind of overwhelmed because XXX will overwhelm me sometimes with what his mood is or what he's going through	
	Increased	TB01 - Interview 1

		confidence	73. I: Do you feel it's given you more confidence? R: I think so, yes, yes. Yes, yes, definitely. TB02 - Interview 2 74. …it validates what you might have thought already, so it kind of gives you a little bit more confidence in what you are doing TB04 - Interview 4 - 75. I feel a lot more confident now. TB06_-_Interview_6 76. I: You mentioned you'd hoped it would make you feel more confident. R: And it did, it definitely did, confident in my own ability, getting it right in my own mind and confident in being able to help my older son as well as help XXXX as well.

Appendix P: Inter-Rater Agreement Calculations of themes by research question

	A	B	C	D	E
1	Inte-rate Agreement Claculation -				
2	Participants' reflections of their experience attending the AEWA programme				
3					
4	Blind rater 1	Inter-rater agreement	calculation		
5		Agreement	Disagreement		
6	Extract 1	4	0		
7	Extract 2	0	3		
8	Extract 3	2	1		
9	Extract 4	2	1		
10	Extract 5	2	0		
11	Extract 6	6	1		
12	Extract 7	2	0		
13	Extract 8	4	0		
14	Extract 9	4	0		
15	Extract 10	2	1		
16	Extract 11	4	0		
17	Extract 12	4	0		
18	Extract 13	4	0		
19	Extract 14	4	0		
20					
21	Total	44	7		51
22				*Percentage Agreement*	86.2745098
23					
24					
25	Blind rater 2	Inter-rater agreement	calculation		
26		Agreement	Disagreement		
27	Extract 1	4	0		
28	Extract 2	0	2		
29	Extract 3	4	0		
30	Extract 4	2	0		
31	Extract 5	2	1		
32	Extract 6	8	1		
33	Extract 7	2	0		
34	Extract 8	2	2		
35	Extract 9	4	1		
36	Extract 10	2	1		
37	Extract 11	4	0		
38	Extract 12	4	0		
39	Extract 13	4	0		
40	Extract 14	0	3		
41					
42	Total	42	11		53
43				*Percentage Agreement*	79.245283
44					

	A	B	C	D	E
1	**Inte-rate Agreement Claculation -**				
2	**Subsequent experiences as a result of attending the AEWA programme**				
3					
4	**Blind rater 1**	**Inter-rater agreement**	**calculation**		
5		**Agreement**	**Disagreement**		
6	**Extract 1**	4	0		
7	**Extract 2**	4	0		
8	**Extract 3**	2	1		
9	**Extract 4**	4	1		
10	**Extract 5**	2	1		
11	**Extract 6**	4	0		
12	**Extract 7**	4	0		
13	**Extract 8**	2	0		
14	**Extract 9**	4	1		
15					
16	**Total**	30	4		34
17				*Percentage Agreement*	88.2352941
18					
19	**Blind rater 2**	**Inter-rater agreement**	**calculation**		
20		**Agreement**	**Disagreement**		
21	**Extract 1**	4	0		
22	**Extract 2**	4	0		
23	**Extract 3**	2	1		
24	**Extract 4**	4	0		
25	**Extract 5**	2	1		
26	**Extract 6**	4	2		
27	**Extract 7**	2	0		
28	**Extract 8**	2	0		
29	**Extract 9**	4	2		
30					
31	Total	28	6		34
32				*Percentage Agreement*	82.3529412
33					
34					