Siblings of Children and Young People with Autism

An Exploration of Typical Siblings' Constructions, Perceptions and Coping Responses

By

Sara Louise Roberts

Doctorate in Educational Psychology (DEdPsy)

2012

Word Count 44.454

Abstract

The inter-sibling relationships of children and young people with autism have generally been overlooked in the literature. Whilst research has increasingly focused on this topic, relatively little is known about the constructions, perceptions and coping responses of typical siblings of children and young people with autism. A child with autism in the family presents a unique challenge and little is known about how this impacts on typical siblings. Typical siblings of children and young people with autism are proposed to be at increased risk for adjustment difficulties, as a result of interactions between complex genetic and environmental variables. Semi-structured, open-ended interviews were conducted with twelve adolescent typical siblings to explore their constructions, perceptions and coping responses. The data was analysed using thematic analysis and nine broad themes emerged: (1) knowledge and understanding of autism; (2) perceptions; (3) the quality of the inter-sibling relationship; (4) the impact of their brothers' condition; (5) coping strategies; (6) perceptions of others; (7) support; (8) the future; and (9) acceptance and ambivalence. These themes were developed into models and the findings present initial evidence which accounts for some variability in typical siblings' constructions, perceptions and coping responses. Such factors have important implications for individual adjustment, inter-sibling relationships, intra-familial relationships and global family functioning. These findings may be used to inform future large scale research designs, with a view to developing comprehensive assessment and support services for typical siblings of children and young people with autism. The Educational Psychologist (EP) will be integral in identifying typical siblings who may be at risk for adjustment difficulties. The EP is also well placed to develop interventions and support services for typical siblings of children and young people with autism. Therefore, this research is direct relevance to the EP, as well as those working with children and young people with autism and their families.

Acknowledgements

Firstly, I would like to extend my gratitude to the gatekeepers, families and young people who contributed to this study and made this project possible. Research is increasingly recognising the challenges that families of children and young people with autism face. I hope that work in this field continues and that support services are developed for typical siblings of children and young people with autism.

Secondly, I wish to thank Professor John Gameson and Dr. Simon Griffey for their support and advice. This project would not have been possible without their valuable guidance and contributions.

Thirdly, I would like to thank my parents, Sue and Clive, for the sacrifices and financial contributions that have enabled me to pursue a career in a field that I am passionate about. Without their constant support, encouragement and belief in me this project would not have been possible. I would also like to thank my Grandmother, Shirley, for being there to offer advice and support. I wish to dedicate this project to my Grandfather, Glyn, who unfortunately cannot be with us to witness this achievement.

Finally, I would like to thank Heather for the practical and emotional support provided throughout this entire process.

List of Nomenclature

ADHD   Attention Deficit Hyperactivity Disorder

APA   American Psychological Association

ASD   Autism Spectrum Disorder

CDD   Childhood Disintegrative Disorder

DAMP   Deficits in Attention, Motor control and Perception

DSM-IV   Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition

EP   Educational psychologist

IPA   Interpretive phenomenological analysis

LEA   Local Education Authority

PDD-NOS   Pervasive Developmental Disorder-Not Otherwise Specified

NAS   National Autistic Society

SEN   Special Educational Needs

SRQ   Sibling Relationship Questionnaire

ToM   Theory of Mind

Contents

Chapter

Appendices

Lists of Tables

List of Figures

Chapter One

Introduction

> We would not think of constructing a case study without collecting the opinions of the adults involved in a situation, so why would we ignore the views of the consumers of education – the children? (Costley, 2000, p. 172)

This research offers a unique opportunity for adolescent siblings of young people with autism to have a voice. This introductory chapter provides an overview of the research title and also provides definitions of terminology used throughout this research thesis. The term 'typical sibling' is used throughout the literature, as well as the current research. This term refers to siblings of children with autism who live in the same family as the child with autism, but do not have any disabilities or additional learning needs. The theoretical significance of this topic will be demonstrated, and subsequently related to the practice of educational psychologists (EPs). The remainder of the research will then be introduced.

The sibling relationship is unique. The nature of the sibling relationship is established during childhood and constitutes one of the most enduring relationships that children experience as it extends into adulthood (Kramer & Bank, 2005; Seltzer, Greenberg, Orsmond & Lounds, 2005; Ross & Cuskelly, 2006). Historically, the literature has tended to focus on the parent-child relationship. The significance of the sibling relationship has been acknowledged in the literature comparatively recently. Howe and Recchia (2006) described that over the past twenty years research has increasingly emphasised the

integral role and function of siblings in the family system. The overall quality of the sibling relationship is important. Siblings form a component of one another's support networks, from which siblings can seek stability and emotional security (Harris & Glasberg, 2003; Milvesky, 2005). Many studies have demonstrated that siblings have a strong impact on the psychosocial development of children in the same family system (Buist, 2010).

As the research has increasingly emphasised the integral role and function of the inter-sibling relationship, attempts have been made to understand how typical siblings are affected when they grow up in a family with a child or young person with a disability (Kaminsky & Dewey, 2002; Verte, Royers & Buysse, 2003; Rivers & Stoneman, 2003). In many cases typical siblings of children and young people with disabilities are not at risk for adjustment difficulties (Bagenholm & Gillberg, 1991; Brody, Stoneman, Davis & Crapps, 1991; Roeyers & Mycke, 1995; Fisman et al., 1996; Stoneman, 2005).

To date methodological and conceptual challenges have hindered progress and findings in the literature are inconclusive. Smith (2010) suggests more recent designs have attempted to advance the knowledge base by using more homogenous groupings of siblings of children with specific difficulties (e.g., autism, Down's syndrome, intellectual disability). In such cases it seems that the unique characteristics associated with specific aetiologies, such as those associated with autism, can impact on the sibling relationships and family functioning (Stoneman, 2005; Gallagher, Powell & Rhodes, 2006).

The term 'autism' refers to a lifelong developmental disability defined in the *Diagnostic and Statistical Manual* (DSM-IV) by three core features: (1) delayed

and disordered communication (language impairment), (2) impaired social communication, and (3) restricted and/or repetitive behaviour (American Psychiatric Association [APA], 1994). Kaminski and Dewey, (2002) posit that children and young people with autism typically present behaviours that can be extremely challenging for all members of the family (e.g., aggressive behaviours, impulsivity, hyperactivity, severe communication deficits). These difficulties may influence global family functioning as well as the quality of relationships and interactions in the family system in a reciprocal nature (Orsmond & Seltzer, 2007). Bagenholm and Gillberg (1991) suggest that typical siblings of children with autism experience more difficulties in the inter-sibling relationship compared to typical sibling dyads. Parents may also be placed under high levels of stress as a result of the demands placed upon them by the child or young person with autism. This increased stress may potentially affect their ability to provide adequate and consistent parenting to typically developing siblings (Morgan, 1988, cited in Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev, 2004; Petalas, Hastings, Nash, Lloyd & Dowey, 2009; Smith & Elder, 2010). Rodrigue, Geffken and Morgan (1993) emphasise that typical siblings may potentially have to cope with changes in family roles, difficulties and stressors in the inter-sibling relationship, restrictions on activities and home structure, feelings of shame and guilt, differential treatment and loss of parental attention as a result of the unique demands associated with having a sibling with autism. A number of studies demonstrate increasing evidence in support of a genetic basis for the aetiology of autism (Bailey et al., 1995; Piven, Palmer, Jacobi, Childress & Arndt, 1997; Piven, 1999; Pickles et al., 2000;

Rutter, 2000). As a result of evidence in support of the broader autism phenotype (BAP) research suggests that a number of typical siblings of children and young people with autism share some of their genetic loading, which may be expressed as a lesser variant of autism (Pilowsky et al., 2004). It may be that a number of siblings of children and young people with autism exhibit difficulties with language, social communication and behaviour. This has implications for the development of positive sibling relationships, parent-child relationships and global family functioning.

As a result of the aforementioned genetic and environmental vulnerabilities associated with autism, typical siblings may be at increased risk for adjustment difficulties. Over the past decade the research 'lens' has increasingly focused on this subgroup within the disability literature in an attempt to understand whether typical siblings of children with autism are at increased risk of developing adjustment difficulties. The literature suggests the majority of typical siblings of children and young people with autism are not at risk of maladaptive psycho-social adjustment outcomes (Kaminsky & Dewey, 2002; Pilowsky et al., 2004; Hastings, 2007; Petalas et al., 2009). Some initial research suggests typical siblings of individuals with autism are in fact better adjusted in terms of specific measures. Studies evidence positive outcomes in terms of improved emotional and behavioural adjustment (Hastings, 2003b) and more positive self-concept (Macks & Reeve, 2007). However, some research indicates that typical siblings of children with autism are at increased risk for a variety of adjustment and coping difficulties (Kaminsky & Dewey, 2001; Hastings, 2003a; Rivers & Stoneman, 2003; Verte, et al., 2003; Seltzer, Abedutto, Krauss,

Greenberg, & Swe, 2004; Ross & Cuskelly, 2006; Orsmond & Seltzer, 2007), as well as impoverished sibling and peer relationships (Kaminsky & Dewey, 2001; Hastings, 2003a). These inconsistencies in the evidence base have prompted fierce debate in the literature.

Some researchers (e.g., Hastings, 2003a; Howe & Recchia, 2006; Macks & Reeve, 2007) suggest the inconsistencies in the literature have resulted from conceptual inconsistencies, methodological differences, tensions between deficit models of disability and social models of disability, as well as inconsistencies in the use of comparison groups. Stoneman (2005) posits that researchers have conceptualised 'adjustment' in different ways (e.g., Kaminsky & Dewey, 2001; Pilowsky et al., 2004) has made it even more challenging to draw conclusions from the literature. The absence of a standardised measure of adjustment outcomes for typical siblings has led to methodological inconsistencies, which has further complicated this issue (Stoneman, 2005; Howe & Recchia, 2006).

In addition to these conceptual and methodological issues, Cuskelly (1999) suggests that 'static' variables, such as individual characteristics (e.g., gender, mental health, age, birth order, age spacing), family characteristics (e.g., socio-economic status) and 'dynamic' factors (e.g., coping, support, knowledge of autism) interact and result in variability in adjustment between individuals. Stoneman, (2005) suggests that research in this field is in its infancy and has called for rigorous research to develop a conceptual understanding of the ways in which typical siblings of children with autism may be placed at increased risk for maladaptive adjustment outcomes. New methods of research need to be

developed in order to address the 'scientific inertia' as researchers "continue to study what has been studied in the past, using methods and measurements that have been used before" (Stoneman, 2005, p. 344). Meadan, Stoner and Angell (2010) argue that research should focus on "hearing the voices of siblings by asking them directly for their perspectives, by attempting to understand their adjustment, and by having them identify areas of needed support" (p. 98).

Recent exploratory qualitative research has provided a wealth of rich data and has provided initial evidence which accounts for variability between individual typical siblings of children and young people with autism (Benderix, Nordstrom & Sivberg, 2006; Mascha & Boucher, 2006; Petalas et al., 2009). These qualitative paradigms have also demonstrated how factors, such as knowledge and understanding of autism, as well as formal support, can benefit typical siblings of children and young people with autism (e.g., Petalas et al., 2009). However, these initial qualitative studies have been subject to a number of methodological criticisms and findings should be interpreted with caution. These studies often fail to triangulate findings, focus on a sample of participants in one geographical location. Furthermore, some authors have failed to conduct follow up interviews with participants, which is significant as the views of participants may be subject to change. Also some previous qualitative studies have failed to acknowledge how individual differences between participants (e.g., participant gender), as well as family characteristics (e.g., birth order) may influence participant accounts. In order to contribute to the knowledge base in this field a decision was taken to adopt a qualitative

paradigm to explore the constructions and perceptions of typical siblings of children and young people with autism. The research was guided by family systems theory and ecological systems theory in an exploratory paradigm. This research question has not previously been addressed in the literature.

Lazarus and Folkman (1984) propose that typical siblings' constructions and personal experiences influence elements of their appraisal process, which can subsequently influence their coping responses. Therefore typical siblings' perceptions and constructions, which are likely to be influenced by a number of factors across different systems, may form an integral role in their appraisals and subsequent coping responses.

The study aims to harness the voices of typical siblings to contribute to the evidence base. The current research thesis will broadly explore how typically developing adolescent siblings construct and experience their relationship with an adolescent brother with autism. Typical sibling coping responses will also be explored. These exploratory research questions are addressed within a family systems and ecological systems theory framework. This has not previously been investigated in the literature, as well as the posited associations between typical sibling constructions, perceptions and coping responses.

It is hoped that the exploratory findings in the current research will inform future large scale studies. This will ultimately help to inform the practice of EPs, as well as other professionals in health and social care. EPs and other professionals are frequently called upon to conduct assessments and provide support to families of children with autism. Barr, McLeod and Daniel (2008) suggest that understanding typical siblings' experiences and needs is essential

for the development of effective sibling support programmes. An incorporation of the child's voice is also considered to be significant in informing evidence based practice for EPs (Harding & Atkinson, 2009). The primary role and function of the EP is concerned with facilitating positive change and improving outcomes for all children (Beaver, 2011). MacKay (2006) proposes that the traditional role of the EP is evolving and EPs are:

> Uniquely placed, in collaboration with others, to provide generic child psychology services, and that it is time for the profession to claim is natural heartland of holistic services to children and young people across the settings of home, school and community. (p. 14).

As EPs work increasingly in consultation at different systemic levels (e.g., individual, family, school, community), it is essential that EPs develop a comprehensive understanding of the variety of issues that can impact on children and young people. EPs are frequently called upon to work with children and young people with autism and their families. Therefore the EP is well placed to identify whether typical siblings may be at risk for adjustment and coping difficulties. Furthermore, the EP will be required to intervene to develop support services at different systemic levels for typical siblings and children and young people with autism.

This chapter introduces the research and provides an overview of some of the conceptual and methodological issues in the literature. The subsequent chapters will provide an in depth review of relevant literature, which will be

subject to critical evaluation. The research questions will be described in more detail. Justification will be provided for the chosen methodology and the research process will be explained. The thematic results will be presented and defined. Qualitative evidence will be provided to support the thematic results. The findings will be cautiously discussed and related to previous research. The limitations of the research will be considered. In light of the results obtained, avenues for future research will be described. The research will then be applied to the role of the EP, as well as other practitioners who work to support children and young people with autism and their families.

Chapter Two

Literature Review

This chapter introduces and critically reviews literature relating typical children and young people with a sibling with a disability. Recent theoretical and research literature related to sibling relationships, typical siblings of children with a disability and siblings of children with autism will be considered. As the review progresses there will be a focus on the adjustment and coping responses of typical siblings of children and young people with autism. Ecological systems theory and family systems theory underpins the current study. These theories will guide an exploration of the factors across different systems that account for variability in adjustment and coping between typical siblings of children and young people with autism. This research will be critically examined and applied to generate some broad exploratory research questions.

This review was guided by information from a variety of sources, including, books and journals from the American Psychological Association, The British Psychological Society and The Association of Educational Psychologists. Information from books and publications from the National Autistic Society were also incorporated in this review. Relevant literature was sourced from Cardiff University and the University Hospital of Wales. Information from peer reviewed journals and online databases, including, Science Direct (V.4 Elsevier), PubMed, Web of Science, ERIC and OVID contributed to this literature review.

An extensive amount of information was considered from a variety of sources, so that no information was excluded from this review.

Numerous searches were conducted to access this information and key word searches included "siblings children autism" "families autism", "sibling relationship", "siblings children disabilities", "sibling coping autism" and "sibling autism support". The vast majority of research relating to typical siblings of children with autism has been conducted more recently. Therefore search attempts related to this topic were limited to information and research published in the past decade. The search for literature and theoretical frameworks relating to typical siblings of children with disabilities has been extended to cover a broader period.

2.1   Conceptual framework and theory

Research examining the sibling relationship does not tend to have a guiding theory. Stoneman (1993, 2005) suggested that research in this area is generally regarded as 'theory free'. The author suggested that existing research on typical siblings of individuals with a disability has generally developed under the umbrella of family systems theory.

Family systems theory was developed on the basis of "organismic or systems metaphors", in order to understand family relationships (Cox, 2010, p.95). The family unit is conceptualised as a "complex integrated whole" (Minuchin, 1988, p.8), where family members exert a continuous and reciprocal influence on one another. This is also known as 'circular causality' (Cox & Paley, 1997, 2003).

Therefore, each family member's behaviours are affected by and subsequently affect other family members' behaviours. Minuchin (1985) asserts that the family system comprises four distinct subsystems (e.g., marital subsystem, parental subsystem, sibling subsystem and the extended family subsystem). The author further suggests that family members are interconnected, so that significant events will impact on all family members in some way (Stoneman & Brody, 1984). Within a family systems framework, child development is proposed to result from transactional regulatory processes between dynamic systems (Cox & Paley, 1997, 2003). An individual is considered to be embedded in a larger family system. Therefore an individual's development, inter-relations and behaviour cannot be fully understood, without giving consideration to the context of their own unique family system (Minuchin, 1985; Sameroff, 1994). Turnbull and Turnbull (2001) adopted a family systems perspective. The authors suggested that the following characteristics should be considered to understand development and global family functioning:

- family characteristics (e.g., family size and form, culture, socioeconomic status, location);

- family interactions (e.g., marital subsystem, parental subsystem, sibling subsystem and extended family subsystem);

- family functions (e.g., affection, socialisation, economics, unconditional love, daily care, self-esteem, spiritual, recreation, education); and

- life cycle stages (e.g., development stages, transitions, birth and early childhood, childhood, adolescence and adulthood).

Firstly, Turnbull and Turnbull (2001) proposed that family characteristics (e.g., family size, family form), personal characteristics (e.g., health, coping, personality) and special challenges (e.g., substance abuse, disability, mental illness) can impact on relationships and global family functioning. Secondly, the quality of relationships and interactions between family members is important in developing a shared understanding of family dynamics. The level of cohesion and independence in a family system is important for harmonious relationships, as well as adaptability in response to stress.

Finally, families serve different roles which change over time. The function that a specific family serves is dependent on the developmental stages of its members. This tends to dictate the functions a family serves for an individual at a given point in time.

Family systems theory may be used to contribute to an understanding of the factors and mechanisms that contribute to child development, adjustment and global family functioning. This theoretical stance asserts that some factors will impact on the quality of intra-familial relationships (e.g., in the sibling subsystem), as well as variations in the ways that family members respond to specific stressors (e.g., having a child with autism). However, it is limited in that it does not acknowledge the role of a number of additional variables that are implicated in the literature.

Traditionally researchers have adopted a single theoretical perspective at the peril of achieving an accurate analysis of variables that contribute to child development and adjustment. This resulted in the development of services and interventions that were predominantly 'within-child'. This is significant as

researchers and professionals in children's services, worked for many years in line with a deficit perspective. Moore (2008) suggested that this method of practice failed to contribute to positive change for children and their families. The author suggested that a deficit perspective failed to acknowledge the many factors that contribute to child development, adjustment and global family functioning.

Bronfenbrenner (1979) made a significant contribution to the theoretical underpinnings of the child development literature, through the conceptualisation of ecological systems theory (Figure 1):
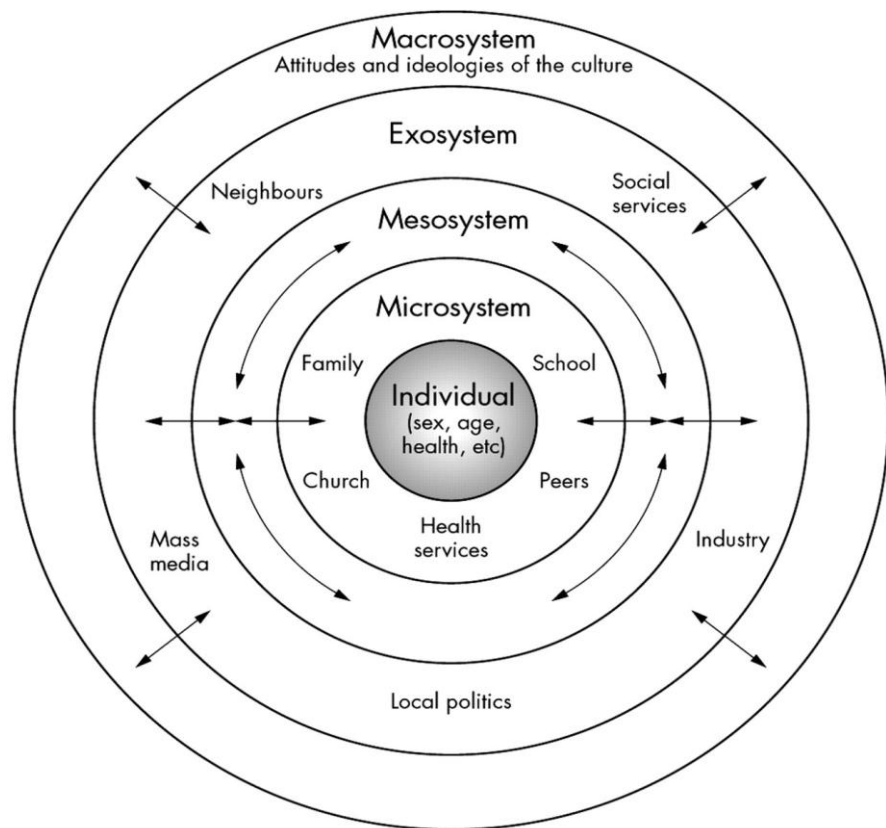
Figure 1: Conceptual Model of Bronfenbrenner's Ecological Systems Theory (adapted from Santrock, & Yussen, 1992).

Bronfenbrenner's theoretical framework challenged deficit perspectives. The author demonstrated that a range of inter-related factors may impact on an individual across different systems at any given time (e.g., microsystem, mesosystem, exosystem and macrosystem). Ecological systems theory emphasises the interaction between more proximal individual factors (e.g., biology, personality), immediate environment (e.g., family, school, peer group), wider environment (e.g., children's services, socio-political factors, industry) and more distal socio-cultural factors (e.g., cultural ideologies).

The theory asserts that an individual's development must be understood through careful consideration of the many factors across systems that contribute to, or impact on development. Furthermore, this perspective asserts that an individual's development occurs as a result of the dynamic, progressive, mutual accommodation of the individual, as well as the environment in which they exist and function (Bronfenbrenner, 1977, 1979, 1986).

As a result of this paradigm shift in the child development literature, more family focused services were developed to address the needs of individual children, as well as their families. Moore (2008) suggested services became more parent-focused as a result of ecological systems theory. Subsequently the needs of other members of the family system (e.g., siblings), began to be recognised. Also, the impact of more distal factors (e.g.., school, socio-economic status, religion) began to be considered. This enabled practitioners to gain an informed appreciation of a child's 'ecocultural niche' (Bernheimer & Weisner, 2007).

Over the past three decades, researchers have increasingly acknowledged the role of distal factors and have examined how they impact on child development, adjustment and global family functioning (Moore, 2008). Guralnick (2005) suggested that as a result of the increased emphasis on more distal factors, there was recognition amongst policy makers of the need to provide specialist services in health, education and the community. The provision of specialist services for children and families at different systemic levels appeared to have a positive impact on individuals, families and communities and was acknowledged in contributing to more positive outcomes (Cooper, Arber, Fee & Ginn, 1999). Ecological systems theory enabled practitioners to conceptualise more complex transactional perspectives and modify aspects of service provision and practice.

Both family systems theory and ecological systems theory capture the importance of understanding an individual's development and adjustment through the environmental context. Smith (2010) suggested that both theories acknowledge "families are comprised of various subsystems that are interrelated" (p. 13). Family systems theory and ecological systems theory have been applied in previous research designs in the disability literature (e.g., Bachraz & Grace, 2009). These perspectives have contributed to the development of an understanding of the challenges families face, as well as variability in adjustment and global family functioning.

These theories will be utilised to guide the current research. The sibling relationship will be conceptualised using a family systems perspective. This theory recognises that the quality of interactions within the family system can

ultimately impact on the adjustment of the individual, the quality of inter-sibling relationships and global family functioning (Brody, Stoneman & MacKinnon, 1996). A typical family system will be affected by a number of significant life events throughout its existence. Certain events (e.g., moving house, conflict, divorce, mental illness, death) are usually perceived as stressors. These stressors will impact on every member of the family system in some way.

Gallagher et al. (2006) suggested that for families of children and young people with a disability, significant life events can be more stressful, compared to families with typical children.

Furthermore, some characteristics of specific disabilities (e.g., autism) will result in some reciprocal influence on all members of the family system (Stoneman, 1993). Smith and Elder (2010) proposed that families of children and young people with autism face a number of unique challenges. These challenges result from the aetiology of this chronic neurobiological disorder. The authors propose that in comparison to other disabilities, autism seems to be "especially taxing for the family system" (p.189).

Through family systems theory and ecological systems theory it may be possible to develop an understanding of how typical siblings of children and young people with autism are affected in different ways, compared to typical siblings of children with other disabilities. These theories will be utilised to inform the current research to explore how variables across different systems impact on typical siblings of young people with autism.

2.2   Introduction to the literature

The first descriptions of autism in clinical settings were provided by Kanner and Asperger in the 1940s. Kanner's (1943) original paper estimated autism was a rare condition with prevalence rates ranging from four to five per 10,000 (Lotter, 1966; Brask, 1972; Wing, Yeates, Brierly & Gould, 1976; Rutter, 1978; Wing & Gould, 1979).

Fombonne (2005a) examined estimated prevalence rates for children with autistic disorder, Asperger's syndrome, childhood disintegrative disorder (CDD) and pervasive developmental disorder not otherwise specified (PDD-NOS) across different countries (Table 1).

Reference	Year	Country	Diagnostic Criteria	Rate/10,000
Lotter	1966	UK	Rating scale	4.1
Wing et al.	1976	UK	Lotter's rating scale	4.8
Wing & Gould	1979	UK	Kanner/triad	4.6/15.7
McCarthy et al.	1984	Ireland	Kanner	4.3
Burd et al.	1987	USA	DSM-III	3.26
Gillberg et al.	1991	Sweden	DSM-III-R	9.5
Fombonne et al.	1992	France	Clinical-ICD-10	4.9
Honda et al.	1996	Japan	ICD-10	21.08
Arvidsson et al.	1997	Sweden	ICD-10	46.4
Baird et al.	2000	UK	ICD-10	30.8
Bertrand et al.	2001	USA	DSM-IV	40.5

Table 1: International Estimates of Prevalence for ASD from 1966-2001 (Adapted from Fombonne, 2005a).

Fombonne (2005a) demonstrated that from 1966 to 2001 estimated prevalence rates for autism across different countries differed significantly

(ranging from 3.26 - 46.4). The author suggested this figure remained relatively stable until the early 1990s then estimates rose significantly (to 21-46 per 10,000).

Other epidemiological studies have been conducted internationally in order to examine the prevalence of autism in the general population. Wing and Potter (2002) suggested these findings range from 3.3 to 60.0 per 10,000. More recently, Knapp et al. (2007) suggested the number of children diagnosed with autism spectrum disorder (ASD) is increasing. The author estimated that there are one in one-hundred children with autism living in the United Kingdom. Although there is some variability in estimates of prevalence rates internationally, some authors suggest that the number of people diagnosed with autism has increased dramatically in more recent years (Newschaffer, Fallin & Lee, 2007). These increases have been attributed to evolving diagnostic criteria, the development of the concept of the autistic 'spectrum', methodological advancements in research, growing awareness, as well as the development of specialist services (Wing & Potter, 2002; Newschaffer et al., 2007). There is also a possibility that a complex variety of genetic and environmental factors are contributing to a true increase.

It is clear that a significant number of families will be affected by having a child in the family with autism (Petalas et al., 2009). Knapp, Romeo and Beecham (2009) suggested that autism impacts on the health, wellbeing, family functioning and social integration of children with autism and their families. The authors investigated the estimated cost of ASDs in the United Kingdom. They concluded that the costs of supporting children with ASDs were estimated

to be £2.7 billion each year. The authors suggested that costs for adults increase significantly to £25 billion annually. It is therefore within everyone's interests to reduce the economic burden and to intervene as early as possible to support children with autism and their families. This will empower families to meet the needs of a young person with autism, within the family system, and reduce the economic burden for society as a whole.

Early classic studies of families of children with disabilities tended to focus on the impact on the inter-parental relationship and directed little attention to the impact on typical siblings (Stoneman, 2005). Parents, primarily mothers, of individuals with autism frequently report increased stress and reduced appraisals of happiness and well-being, in comparison to parents of typical children, or children with other disabilities (Weiss, 2002; Abbeduto et al., 2004; Duarte et al., 2005; Hastings et al., 2007; Herring et al., 2006). The literature suggest that increased stress can have a negative impact for parent mental health, as well as increased inter-parental conflict. This may subsequently have implications for parenting capacity and global facility functioning. It is crucial that the true impact on siblings is established, as familial stress has been associated with maladaptive adjustment in children and young people (Gass, et al., 2007).

Benson and Karlof (2008) posited that it is important to understand why typical siblings of children with disabilities, such as autism, have more adjustment difficulties from both an applied and theoretical perspective. The authors suggested research in this area is crucial in informing intervention and support services. Furthermore, clarity is required to ascertain which factors account for

variability in adjustment outcomes between individuals (Labato, 1993, cited in Benson & Karlof, 2008).

2.3 Typical sibling relationships from childhood to adolescence

In comparison to inter-parental and parent-child relationships, sibling relationships have received less attention in the literature and the dynamics of sibling relationships are less understood (Feinberg et al., 2003). Research designs that acknowledge the inter-sibling relationship increasingly emphasise the unique effects it has on child development, adjustment and global family functioning (Stoneman, 2005).

The sibling relationship is unique and many studies have demonstrated that siblings have a strong impact on the psychosocial development of children in the same family system (Buist, 2010). During childhood siblings are important as they form a component of one anothers' support networks, from which each individual can seek stability and emotional security (Harris & Glasberg, 2003). The nature of the sibling relationship is established during childhood and constitutes one of the most enduring relationships that children experience, as it extends into adulthood (Kramer & Bank, 2005; Seltzer et al., 2005; Ross & Cuskelly, 2006). Although constructs of the sibling relationship vary between cultures, the sibling relationship is extremely important. It provides children with the opportunity to develop a range of skills, such as emotional literacy, self control, social skills and play skills (Gibb, 1993; Sanders, 2004; McHale, Kim & Whiteman, 2006). Ross and Cuskelly (2006) suggested that the quality of the

inter-sibling relationship contributes directly to the psychological adjustment and wellbeing of children and young people.

In the disability literature, research has typically contrasted the sibling relationships of typical sibling dyads with sibling dyads where one child has a disability. It is important to develop an understanding of the nature of typical sibling relationships, as well as the variables that affect it, as this is so regularly used as the 'gold standard' in the disability literature (Stoneman, 2005).

In typical sibling dyads the sibling relationship is subject to change throughout development. Smith (2010) described that the sibling relationship changes as children develop and progress into adolescence, in a way that is unique and different from parent-child or peer relationships. The sibling relationship is generally considered to go through periods of intense activity and inactivity in a cyclical nature, resulting in age related differences in role symmetry, warmth/closeness and conflict/rivalry (Bank & Kahn, 1997).

Furman and Buhrmester (1985) developed the Sibling Relationship Questionnaire (SRQ). The SRQ assesses the quality of inter-sibling relationships. The authors demonstrated that four main constructs contribute to inter-sibling relationship quality in typical sibling dyads (e.g., warmth/closeness, relative status/power, conflict and rivalry). Warmth and closeness are characterised by intimacy, prosocial behaviour, nurturance, companionship and admiration. Relative status/power are characterised by the level of symmetry in the relationships, nurturance and dominance. Conflict and rivalry are characterised by quarrelling, antagonism, competition and dominance.

Buhrmester and Furman (1990) explored developmental trends in the quality of sibling relationships. The purpose of this research was to explore child perceptions of inter-sibling relationship quality in typical sibling dyads from early childhood to adolescence. The researchers demonstrated that perceptions of warmth and closeness tend to be higher during childhood and decrease during adolescence. The authors posit this may be due to increased emphasis on peer relationships, as well as less time spent in the family home and decreased opportunities for interactions between siblings (Cicirelli, 1995). In terms of conflict and rivalry, Buhrmester (1992) suggested sibling relationships tend to be typified by high levels of conflict and rivalry during childhood and early adolescence, which declines as children progress into middle-late adolescence. Similarly to warmth and closeness, the author suggests that this decline is a result of a decrease in the amount of time siblings spend in mutual interactions within the family. Gallagher et al. (2006) suggested that during early childhood siblings frequently interact with one another. Furthermore, siblings engage in play and experiential learning on a mutual basis. As siblings are likely to spend more time together in early childhood, this period presents a number of opportunities for conflict to occur. However, as siblings progress into adolescence and spend less time together, this reduces the opportunity for inter-sibling conflict and disagreements (Buhrmester and Furman, 1990). Brody (1998) suggested a healthy amount of conflict is beneficial to the quality of sibling relationships and provides an opportunity for siblings to engage in communication and express their emotions.

In terms of role structure, the most significant difference appears during childhood and decreases as children progress into adolescence (Smith, 2010). Researchers suggest that the inter-sibling relationship tends to be asymmetrical during childhood, with older siblings supporting the development and care of younger siblings (Buhrmester and Furman, 1990; Stoneman, 2001). As children progress into adolescence the sibling relationship tends to become more symmetrical and egalitarian, which researchers suggest is the result of increased independence, growing confidence and increased developmental status (Cicirelli, 1995; Stoneman, 2001).

In additional to life course variables some additional variables have been found to influence the quality of inter-sibling relationships in typical sibling dyads. These variables are referred to as "constellation variables" in the literature (Smith, 2010, p. 16). Buhrmester (1992) suggested these variables include gender, birth order and age spacing.

In terms of gender, females tend to report higher levels of warmth and closeness in same-sex female dyads in comparison to same-sex male dyads (Furman & Buhrmester, 1985). Female dyads also tend to report increased intimacy, companionship, admiration and similarity compared to male dyads (Buhrmester and Furman, 1990).

Birth order has also been found to influence the quality of inter-sibling relationships in typical dyads, with older siblings reporting increased dominance over younger siblings (Smith, 2010). Furthermore, younger siblings report greater admiration of their older sibling (Buhrmester and Furman, 1990). The literature suggests that birth order does not appear to influence levels of

conflict and rivalry, which appear to be moderated by differential parental treatment (Buhrmester and Furman, 1990). Older siblings describe that their relationships are more conflicted when they perceive younger siblings are favoured more by parents (Buhrmester and Furman, 1990; Kowal & Kramer, 1997).

Age spacing in typical dyads appears to exert consistent effects across the constructs of warmth, closeness, status, conflict and rivalry (Smith, 2010). Buhrmester and Furman (1990) proposed children report increased warmth, closeness, affection, prosocial behaviour, admiration and less intimacy in wider spaced dyads (four or more years) compared to narrow spaced dyads (less than three years). Furthermore, the authors suggest that in terms of status, older siblings in wider spaced dyads report they frequently provide nurturance and care to younger siblings. Older siblings are also admired more by younger siblings (Buhrmester and Furman, 1990). The authors suggested that increased levels of dominance, conflict and competition were reported in narrow spaced dyads.

Buhrmester and Furman (1990) suggested the aforementioned constellation variables all exert consistent effects on perceptions of the quality of typical inter-sibling relationships. These results have been replicated in more recent studies (Stoneman & Brody, 1993; Bank & Kahn, 1997).

Furthermore, additional factors, such as child temperament, child age, parenting behaviours and the inter-parental relationship have also been found to exert effects on perceptions of the quality of the inter-sibling relationship in typical dyads (Azmitia & Hesser, 1993; Stoneman & Brody, 1993; Newman,

1994; Samalin, 1996; Bank & Kahn, 1997; Brody, 1998). Smith (2010) asserts findings should be interpreted with caution as the majority of these effect sizes tend to be relatively small, with the exception of birth order.

In summary, the literature suggests that a range of variables (e.g., child gender, birth order, age spacing, child temperament, child age, parenting behaviours, inter-parental relationship) contribute to perceptions of the quality of the inter-sibling relationship in typical dyads. Perceptions of the quality of the inter-sibling relationship has implications for adjustment and global family functioning. Therefore, findings from studies with typical sibling dyads have been extended to explore perceptions of the quality of the inter-sibling relationship for typical siblings of children and young people with a disability.

2.4 Typical sibling relationships of children and young people with a sibling with a disability

Stoneman (2005) suggested that researchers have tended to conceptualise and compare relationships of typical siblings with siblings of young people with a disability. The author suggested this is the result of the absence of a guiding theory to anchor research. In the literature researchers have explored how the relationships of typical sibling dyads differ from sibling dyads where a child has a disability.

Early research in the disability literature was traditionally guided by the assumption that having a sibling with a disability would result in maladaptive adjustment for typical siblings (Petalas et al., 2009; Smith, 2010). However, this is not always the case and the research in the literature is inconclusive.

Some researchers have demonstrated no group differences in externalising and internalising difficulties for typical siblings of children with a disability (e.g., Gold, 1993; Lynch, Fay, Funk & Nagel, 1993; Cuskelly, Chant, & Hayes, 1998; Stores, Stores, Fellows, & Buckley, 1998; Hannah & Midlarsky, 1999; McMahon, Noll, Michaud, & Johnson, 2001; Kaminsky & Dewey, 2002; Pilowsky et al., 2004).

Conversely, other researchers have found clinically significant levels of externalising and internalising difficulties in siblings of children and young people with autism (Rodrigue et al., 1993; Fisman et al., 1996; Fisman, Wolf, Ellison & Freeman, 2000; Hastings, 2003a; Verte et al., 2003), Down's syndrome (Cuskelly & Dadds, 1992; Cuskelly & Gunn, 2003), severe/profound mental retardation (Coleby, 1995) and mixed disabilities (Nixon & Cummings, 1999). A number of studies have examined the self-concept of typical siblings of children and young people with a variety of disabilities. These studies have consistently demonstrated no differences in self concept or perceived competence (Bagenholm & Gillberg, 1991; Bischoff & Tingstrom, 1991; Lynch et al., 1993; Burton & Parks, 1994; Dyson, 1996; Hannah & Midlarsky, 1999; Fisman et al., 2000; McMahon et al., 2001; Singhi, Malhi & Dwarka, 2002; Verte et al., 2003).

Stoneman (2005) draws attention to findings in the literature and suggested that siblings of children with disabilities have low self concept and self esteem. The author suggested that typical siblings of children and young people with a disability exhibit increased adjustment difficulties.

Gold (1993) found that siblings of children and young people with autism were at increased risk for depression. In another study McMahon et al. (2001)

demonstrated no differences in depression between typical siblings of children with acquired brain injury and a normal control group.

Rossiter & Sharpe (2001) conducted a meta analysis of fifty-one published studies of siblings of children with a chronic illness. The authors concluded that modest, negative effect sizes existed for siblings of children with a chronic illness relative to comparison participants. Furthermore, parent reports were more negative than child reports. In addition to these findings the authors also demonstrated that psychological functioning (i.e., depression, anxiety), peer activities, and cognitive development scores were lower for siblings of children with a chronic illness compared to typical controls.

Other research in the literature challenges these findings. Some studies suggest that typical children and young people who have a sibling with a disability are better adjusted. Stoneman (2005) demonstrated that typical siblings of children with a disability have more positive perceptions of their sibling with a disability and the quality of the inter-sibling relationship in comparison with typically developing sibling dyads.

Some researchers suggest typical siblings thrive as a result of having a sibling with a disability and are psychologically stronger as a result (Taunt & Hastings, 2002; Stoneman, 2005). Some siblings of children with disabilities have been found to be better adjusted for specific outcomes (e.g., self efficacy, locus of control). Burton and Parks (1994) found that adolescent siblings of individuals with disabilities had higher internal locus of control in comparison to typical control dyads.

Roeyers and Mycke (1995) conducted an investigation into sibling relationships of sixty children. Self-report data were collected from twenty siblings of children with autism, twenty siblings of children with intellectual disability and twenty siblings of typical children. There were no significant differences in self report data with respect to the overall quality of the sibling relationship. Furthermore, siblings of children with intellectual disability and autism reported they were more positive and accepting of their sibling's disability compared to typical siblings.

Kaminski and Dewey (2001) utilised self report data from the SRQ (Furman & Buhrmester, 1985) to examine inter-sibling relationship quality in thirty siblings of children with autism, thirty siblings of children with Down's syndrome and thirty typical siblings. Typical siblings of children with Down's syndrome appeared more nurturing and caring towards their sibling. These typical siblings also reported their relationships were closer, compared to typical siblings of children with autism and typical sibling dyads. Typical siblings of children with autism reported their relationship with their sibling with autism was positive, despite the fact that they experienced less intimacy and prosocial behaviour in contrast with comparison groups and typical controls. Siblings of children with autism and Down's syndrome also reported greater admiration and less competition and conflict in comparison to typical sibling dyads.

Grissom and Borkowski (2002) found no differences between adolescent siblings of young people with a disability and comparison young people in a study focusing on self efficacy.

Other research suggests that siblings of children with disabilities demonstrate higher levels of empathy and patience (Stalker & Connors, 2004; Benderix & Sivberg, 2007).

Cuskelly and Gunn (2003) explored the inter-sibling relationships of children with Down's syndrome and typical sibling dyads. The authors utilised self report data from fifty-four participants. The results indicated that having a sibling with Down's syndrome did not impact on the overall quality of the inter-sibling relationship. In fact, typical siblings of children with Down's syndrome had more positive relationships compared to typical siblings.

Barr et al. (2008) compared the inter-sibling relationships of six children (aged five to eight years) with communication impairments and their typical siblings (aged five to fourteen years) in a qualitative experimental design. The authors administered semi-structured interviews about activity and participation in society. Thematic analysis indicated there was little impact on typical siblings' perceptions of the quality of the inter-sibling relationship. Typical siblings spoke positively about their experiences and indicated that they enjoyed engaging in joint activities with their sibling with communication impairments. These findings provide initial evidence for some themes that may account for variability in typical siblings' perceptions of their sibling with a disability and perceptions of the quality of the inter-sibling relationship.

Some authors have attempted to explore how a range of variables impact on typical siblings' perceptions of inter-sibling relationship quality when a child or young person has a disability. The literature suggests that one of the main differences is the nature of roles and relationships. In typical sibling dyads, as

siblings increase in age and developmental status, the relationship tends to become more egalitarian and symmetrical. In sibling dyads where a child has a disability roles tend to remain fairly asymmetrical, irrespective of the age or developmental status of the sibling with the disability (Smith, 2010). For older typical siblings, their relationship tends to remain asymmetrical, as they may adopt more supportive and caring roles (Stoneman, 2001).

Younger siblings of children with a disability tend to demonstrate 'role crossover', where younger typical siblings advance in terms of developmental status and subsequently assume more dominant roles in the inter-sibling relationship (Farber, 1960, cited in Smith, 2010). This trend remains constant as siblings progress into adolescence (Eisenburg, Baker & Blacher, 1998). Eisenburg et al. (1998) utilised questionnaire data from the SRQ (Furman & Buhrmester, 1985), as well as interview data to explore inter-sibling relationships of typical siblings of children with a disability. Data were collected from twenty-five typical siblings of children with an intellectual disability that resided in the family home, twenty siblings of children with an intellectual disability that were in respite and twenty-eight siblings of typical siblings (e.g., typical controls). The control group of typical adolescent participants reported having equal power and status, whereas younger adolescent siblings of children with an intellectual disability perceived they had more power and status in their relationship with their sibling with a disability. The authors suggested that this asymmetry in role relationships was the result of younger siblings spending increased time engaging in caretaking activities to support the needs of their older sibling.

Stoneman, Brody, Davis, Crapps and Malone (1991) examined the nature of role relationships of siblings of children with intellectual disability. The authors investigated the types of roles ascribed by parents in a sample of thirty two sibling dyads, where a sibling had an intellectual disability. These types of roles included monitoring, assisting with daily care needs and babysitting. Typical siblings were observed during play interactions. The authors found that younger typical siblings of children with intellectual disability tended to assume roles (e.g., physical care) that would normally be expected of older siblings. Hannah and Midlarsky (2005) explored altruistic and prosocial behaviours of fifty siblings of children with intellectual disability and fifty siblings of typical children. Typical siblings of children with intellectual disability tended to provide more care and emotional support to their sibling with intellectual disability, compared with typical siblings. These findings are consistent with earlier research and support the notion that younger siblings of children with intellectual disability assume more dominant roles. Therefore inter-sibling relationships are more asymmetrical through the course of development. Smith (2010) suggests that this asymmetry in sibling roles and relationships does not tend to have a negative effect on sibling perceptions of the overall quality of the inter-sibling relationship (Smith, 2010).

As with typical sibling dyads, constellation variables (e.g., birth order, child gender, child age, age spacing) also impact on the inter-sibling relationship when a child or young person has a disability.

In terms of gender the findings in the literature have been fairly inconsistent and contradictory (Smith, 2010). Research suggests that males engage in more

caring and altruistic behaviours to support the needs of their sibling with a disability, in comparison with typical sibling dyads. However, female sisters of children with a disability appear to engage in more caring behaviours, teaching and behaviour management compared to male siblings of children with a disability (Brody et al., 1991; Stoneman et al., 1991; Hannah & Midlarsky, 2005). Some research has challenged these findings. Cuskelly and Gunn (2003) reported no significant differences in caring behaviours as a function of the gender of the typical sibling.

Birth order and age spacing appear to have an impact on perceptions of the quality of the inter-sibling relationships when a child has a disability. Smith (2010) suggested that this is the result of 'role crossover' and the asymmetry that typically occurs in inter-sibling relationships where a child or young person has a disability. The literature suggests that younger typical siblings of children and young people with a disability adopt more caring and altruistic roles in comparison to typical sibling dyads (Stoneman et al., 1991; Hannah & Midlarsky, 2005).

In summary, the findings in the literature present initial evidence which suggests that a number of variables may impact on perceptions of the quality of the inter-sibling relationship when a child or young person has a disability, as with typical sibling dyads. This may account for the degree of variance that is evident between individual sibling groups. Furthermore, a proportion of studies suggest children and young people with a disability are at risk for maladaptive adjustment outcomes. However, some studies describe that typical siblings are better adjusted in comparison to typical controls. Therefore the research

indicates that typical siblings of children and young people with disabilities are not automatically at risk for maladaptive adjustment as a function of growing up with a sibling with a disability (Bagenholm & Gillberg, 1991; Brody et al., 1991; Roeyers and Mycke, 1995; Fisman et al., 1996; Stoneman, 2005). The literature suggests that there is a degree of variance in typical siblings' perceptions of inter-sibling relationship quality. This appears the be affected by the developmental stage of typical siblings and a range of other variables (e.g., constellation variables).

2.5 Typical sibling relationships of children and young people with a sibling with autism

A number of researchers (e.g., Sharpe & Rossiter, 2002; Stoneman, 2005; Smith, 2010) have critically evaluated the findings in the disability literature. These authors suggest that a number of studies (e.g., Dyson, 1989, 1996; Fisman et al., 2000) in the literature used heterogeneous groups of children with a broad range of disabilities (e.g., Down's syndrome, autism, intellectual disability, cerebral palsy) and contrasted findings with typical sibling dyads, which tend to constitute a control group.

Smith (2010) suggested more recent designs have attempted to advance research by using more homogenous groups of siblings of children with specific difficulties (e.g., autism, Down's syndrome, intellectual disability). In such cases it seems that some characteristics associated with specific disabilities or disorders can impact on the inter-sibling relationship in unique ways (Stoneman, 2005; Gallagher et al., 2006).

Furthermore, the use of heterogeneous groupings and pathology models of research may have skewed the findings in the literature. In order to overcome these methodological and conceptual difficulties, Stoneman (2005) asserted that designs need to incorporate more stringent grouping methods to examine how specific disabilities/disorders impact on inter-sibling relationship quality.

Autism is a disorder characterised by 'impaired development in social interaction and communication and a markedly restricted repertoire of activities and interests' (American Psychiatric Association, 2000, p.70). Jordan (2004) suggested children with autism often have difficulty with reciprocity in social exchanges, as well as with social communication. The disorder is also typified by language impairment.

Kaminski and Dewey (2002) described that children and young people with autism typically present behaviours that can be extremely challenging for all members of the family (e.g., aggressive behaviours, impulsivity, hyperactivity, sleep disorder, severe communication deficits). These difficulties may influence global family functioning as well as the perceptions of inter-sibling relationship quality and global family functioning (Orsmond & Seltzer, 2007). Furthermore, Bagenholm and Gillberg (1991) posited that typical siblings of children with autism experience more difficulties in the inter-sibling relationship, compared to typical sibling dyads.

A family systems and ecological systems perspective asserts that growing up in a family where a child or young person has autism will have a reciprocal impact on all family members, including typical siblings.

Kaminski and Dewey (2001) suggested that typical siblings of children and young people with autism may be at risk of adjustment difficulties as a function of the deficits in social communication and theory of mind (ToM) associated with autism. Moreover, parents may be placed under high levels of stress as a result of the demands placed upon them by the child or young person with autism. This may potentially affect their ability to provide adequate parenting to typically developing sibling (Morgan, 1988, as cited in Pilowsky et al., 2004; Petalas et al., 2009; Smith & Elder, 2010).

As a result of the genetic and environmental factors discussed previously, it is crucial that research designs attempt to understand how the inter-sibling relationship is affected when a child has autism. The rationale for this is such that the unique aetiological characteristics associated with autism may place typical siblings at increased risk for difficulties. Genetic and environmental factors may accumulate and have a negative impact on the quality of the inter-sibling relationship, intra-familial relationships and global family functioning to a far greater extent than other typical siblings of children and young people with disabilities.

A review of recent research on the adjustment and perceptions of typical siblings of children and young people with autism has produced inconsistent findings (Pilowsky et al., 2004; Bachraz & Grace, 2009; Petalas et al., 2009; Smith & Elder, 2010). However, Petalas et al. (2009) described that research in this area is still in its infancy.

Some research indicates that some typical siblings are at increased risk for a variety of adjustment and coping difficulties, psychological maladjustment and

poor self-concept (Kaminsky & Dewey, 2001; Hastings, 2003a; Rivers & Stoneman, 2003; Verte et al., 2003, Roeyers, & Buysse, 2003; Seltzer et al., 2004; Ross & Cuskelly, 2006; Orsmond & Seltzer, 2007). Additional research indicates that typical siblings of children and young people with autism may be likely to experience impoverished sibling and peer relationships as a result of impaired social competence (Fisman et al., 2000; Kaminsky & Dewey, 2001; Hastings, 2003a; Lobato, Kao & Plante, 2005).

Stoneman (2005) suggested that the aetiological differences associated with autism can affect inter-sibling interactions. The deficits associated with autism may impact on the way in which typical siblings are able to initiate play, interact and communicate with their sibling with autism (Smith, 2010). Having a sibling with autism has been found to have a negative impact on the development of cognitive and language skills during the early years (Gamliel, Yirmiya & Sigman, 2007). Other studies demonstrate that having a sibling with autism can impact on the development of play skills during infancy (Christensen et al., 2010). At thirty-six months typical siblings of children with autism have been found to have receptive and expressive language difficulties compared to typical sibling dyads (Yirmiya, Gamliel, Shaked & Sigman, 2007). Toth et al. (2007) also demonstrated that typical siblings of children with autism were below average in expressive language and composite IQ, had lower mean receptive language skills, and poor behaviour and social communication in toddlers aged eighteen to twenty-seven months. The authors concluded that the development of typical siblings of children with autism was affected during infancy. The authors suggest that the development of non-autistic siblings

should be closely monitored as a function of the BAP and the reciprocal influence of the child with autism on the typically developing sibling.

In contrast, some research suggests that there are no significant differences in the psychological adjustment of children and young people with a sibling with autism in the family (Kaminsky & Dewey, 2002; Verte et al., 2003; Pilowsky et al., 2004; Hastings et al., 2007; Petalas et al., 2009).

A number of studies suggest that having a sibling with autism engenders positive outcomes for typical siblings (Bachraz & Grace, 2009). Several studies propose that typical siblings of individuals with autism are actually better adjusted and typical sibling participants describe that having a sibling with autism has a positive impact on their lives (Petalas et al., 2009; Smith & Elder, 2010). Some researchers suggest that having a sibling with autism has a positive impact on typical siblings, in terms of improved emotional and behavioural adjustment (Hastings, 2003b), as well as more positive self-concept and improved social competence (Kaminski & Dewey, 2002; Verte et al., 2003, Roeyers & Buysse, 2003; Macks & Reeve, 2007). Furthermore, parents and siblings of children and young people with autism report a number of positive effects, such as increased sensitivity, empathy, maturity and responsibility (Hastings & Taunt, 2002; Dykens, 2005).

O'Brien, Slaughter and Peterson (2011) found that in contrast to the aforementioned findings from typical siblings in infancy, typical older siblings (aged 3.67 to 12.67 years) have better developed social-cognitive skills. The authors suggest that older siblings may over-compensate for the ToM deficits of their younger sibling with autism. For example, older siblings may

communicate on behalf of their younger siblings, which will have negative implications for the socio-cognitive and emotional development of the younger sibling with difficulties.

Older typically developing siblings of children and young people with autism have also been found to support with teaching and behaviour management. Some researchers indicate this has a positive impact on typical siblings and results in fewer behaviour problems (Dyson, 1996; Ross & Cuskelly, 2006).

There are a number of inconsistencies in the literature and it appears that a number of variables (e.g., birth order, child age) impact on the development and adjustment of typical siblings. Some authors (e.g., Bachraz & Grace, 2009; Petalas et al., 2009) suggest that these inconsistencies in quantitative research have emerged as a result of adopting a pathology model to guide research. Bachraz and Grace (2009) posited that by starting from a "position of assumed negative consequences unless proven otherwise is to pathologise children and their families" (p. 318).

In summary, there is evidence which suggests that the aetiology of autism (e.g., impairments in social communication) can impact on the development and adjustment of typical siblings, as well as the quality of the inter-sibling relationship. The aetiology of autism (e.g., social-communication impairments, cognitive impairments and language impairments) has been found to have a negative impact on typical sibling development and interactions during the early years (e.g., Gamliel, et al. 2007; Toth et al., 2007; Yirmiya et al., 2007; Christensen et al., 2010;). These effects appear to be particularly salient during infancy and decreases as a function of development. As typical siblings progress

through childhood and into adolescence, studies suggests that typical siblings describe both positive and negative aspects of the inter-sibling relationship, when a child or young person has autism (e.g., Petalas et al., 2009). This has implications for subsequent adjustment and indicates that not all children and young people will be at risk for maladaptive adjustment. The developmental stage of siblings is clearly important and further research is needed, in order to focus on complex developmental issues. Designs need to include narrower age groups in longitudinal designs to address these issues (Orsmond & Seltzer, 2009).

Typically developing siblings of children and young people with autism also appear to be affected by a range of other variables. As a result of recent developments and more stringent and rigorous experimental designs, researchers are increasingly considering how a range of variables impact on typical siblings' perceptions of the quality of the inter-sibling relationship, when a child or young person has autism. Constellation variables, such as family size, appear to moderate the negative impact on typical siblings (e.g., Harris & Glasberg, 2003). Distal factors, such as embarrassment and differential treatment (e.g., Bachraz & Grace, 2009) have also increasingly being implicated. Descriptive and exploratory studies have begun to examine how a variety of variables (e.g., gender, birth order, age, coping styles, family resources, perceptions) contribute to the quality of the inter-sibling relationship, when a child or young person has autism. Smith and Elder (2010) suggested that a combination of fixed variables (e.g., family size, socio economic status, sibling age) and dynamic variables (e.g., depression, conduct, self-concept) may exert

an influence on typical siblings' perceptions of their sibling with autism. As previously discussed, this has implications for the quality of inter-sibling relationship, as well as typical sibling adjustment.

2.6 What factors predict variability in inter-sibling relationships when a child or young person has autism?

Buhrmester and Furman (1990) emphasised that inter-relations between all members of a family system reflect a founding component of the family framework. This framework has recently been extended to investigations involving typical siblings of children with autism (Petalas et al., 2009).

Smith and Elder (2010) draw attention to the strategic plan for autism related disorders published by the National Institute of Health (NIH). This guidance emphasises the importance of considering positive and negative factors in each family environment to generate an accurate evaluation and assessment of typical sibling health and wellbeing. The authors also suggested that despite the fact that clinical research dominates the literature, some variability in typical sibling adjustment may be attributable to psychological, sociological and ecological factors. These factors may be associated with the family system and the wider systemic context. It is possible that a variety of complex genetic and environmental factors interact in unique ways and subsequently impact on the quality of the inter-sibling relationship and typical sibling adjustment (Tomeny, Barry & Bader, 2012).

Lynch et al. (1993) proposed that a family system typified by high levels of disorganisation and conflict has a deleterious impact on siblings of children

with disabilities, in comparison to typically developing dyads. Nixon and Cummings (1999) suggest that siblings of children and young people with disabilities are attuned to family conflict and specific stressors. High levels of parental stress and low resource availability have been associated with increased behaviour problems and reduced social competence in siblings of children and young people with disabilities (Cuskelly et al., 1998; Fisman et al., 1996, 2000; VanRiper, 2000; Dyson, 2003).

Cuskelly (1999) examined how factors at different levels in the family system impact on typical siblings of children with disabilities. The author distinguished between dynamic variables (e.g., coping skills) and static variables (e.g., birth order, gender). Cuskelly (1999) suggested that developing an understanding of the way in which dynamic variables impact on typical siblings of children with autism could be beneficial in the development of support services. The author reasoned that dynamic variables are more open to change and may be more responsive to targeted interventions. Although research on the role of dynamic variables is in its infancy, studies are now beginning to consider how a variety of dynamic variables account for variability in the inter-sibling relationship. Stoneman (2005) indicated that there is a degree of variability in sibling relationships when a child or young person has autism. The extent to which the quality of the inter-sibling relationship is affected, appears to depend on a number of variables across different systems (Harris & Glasberg, 2003; Bachraz & Grace, 2009; Petalas et al., 2009; Smith and Elder, 2010; Tomeny et al., 2012).

McHale, Sloan and Simeonsson (1986) pioneered an investigation into factors that impact on the inter-sibling relationships of children with autism. The authors demonstrated that siblings of children with autism experienced increased stress in comparison to siblings of children with other disabilities and typically developing siblings. Further to this the authors demonstrated that siblings appear to be at risk of adjustment difficulties when the family system was typified by:

- poor relationships;

- marital conflict; and/or

- parental depression or other psychiatric illnesses.

The authors demonstrated that warm and intimate family systems typified by positive relationships, can have a protective affect on typical siblings, irrespective of the severity of their siblings' autism. In terms of the inter-sibling relationship, typical siblings of children with autism perceived their relationship more positively when:

- the child with autism was accepted as a member of the family;

- they perceived minimal differential attention and treatment by parents;

- they had fewer worries about the future;

- they were from a larger family;

- they were older that their sibling with autism;

- there was greater age spacing (four or more years) between siblings;

- they had well developed coping abilities; and

- they had experienced positive responses from parents and peers.

Rodrigue et al. (1993) discovered lower self competence scores in typical siblings of children with autism and found their psychological adjustment was affected by sibling age, family size, and marital status. Parent depression has been associated with typical sibling behavioural difficulties in families where a child has autism (Benson, Gross & Kellulm, 1999; Cuskelly & Dadds, 1992).

Fisman et al. (1996) investigated the adjustment of forty-six typical siblings of children with pervasive developmental disorder not otherwise specified (PDD-NOS), forty-five siblings of children with Down's syndrome, and forty-six typical children (serving as controls) in a three year longitudinal study. A range of direct and indirect variables associated with sibling adjustment were considered. The authors found that marital satisfaction, lack of parental depression, a cohesive family and a warm, non-conflictual sibling relationship acted as protective factors for typical siblings and typical siblings of children with Down's syndrome. However, these findings did not extend to typical siblings of children with PDD-NOS. The authors concluded that transactional models should be applied to support the identification of risk and protective factors that are implicated in typical sibling adjustment.

More recently, Macks and Reeve (2007) concluded that the adjustment of typical siblings of children with autism is affected by variables such as family size, birth order and socio economic status of the family.

Smith and Elder (2010) suggested that initial investigations correlated gender, birth order, family size, socioeconomic status and sibling age with typical sibling adjustment. The authors proposed that maternal depression, coping resources, family support, conduct and typical siblings' perceptions of the child with autism can impact on the quality and nature of the inter-sibling relationship. Benderix and Sivberg (2007) conducted face to face interviews with fourteen siblings aged between five and twenty-nine years of age from five families to explore typical siblings' experiences of having a sibling with autism. A qualitative method was employed and content analysis was employed as the method of data analysis. Seven themes were found to contribute to the variability in typical siblings' experiences of having a sibling with autism:

- having a sense of responsibility;

- feeling sorry for their sibling with autism;

- dealing with abnormal behaviour;

- feeling empathy for their sibling with autism;

- expressing hope and anticipating relief through respite;

- experiencing violent behaviour; and

- negative impact on siblings' peer relationships.

Additional research in the literature has implicated variables such knowledge of autism (Dellve et al., 2000; Howlin et al., 2002; Harris & Glasberg, 2003), spending time together (Lobato et al., 1991; Knott, Lewis and Williams (1995); Strain & Danko, 1995; Heller et al., 1999), caretaking responsibilities and role

demands (Stoneman et al., 1991; Coleby, 1995; Cuskelly & Gunn, 2003; Stoneman, 2005), family climate (Dallas et al., 1993; Howell et al., 2007) and differential parenting (Lobato et al., 1991; Corter et al., 1992; McHale & Pawletko, 1992; Fisman et al., 2000; Stoneman, 1998, 2005). These variables have been found to impact on the quality of the inter-sibling relationship, typical sibling adjustment and global family functioning in families where a child or young person has autism. It is crucial that these factors are subject to further examination. Stoneman (2005) suggested that well-functioning families provide siblings with the necessary support and security to thrive. Positive inter-parental interactions support family cohesion and this subsequently results in low intra-familial conflict. This consequentially fosters positive inter-sibling relationships, where typical siblings have more positive self-concept and are more adaptive to stressors and demands. This subsequently places typical siblings at a reduced risk for developing adjustment difficulties (Cuskelly & Dadds, 1992; Rodrigue et al., 1993; Benson et al., 1999; Mandleco et al., 2003; Rivers & Stoneman, 2003).

Petalas et al. (2009) linked their findings to the field of psychological stress theory. Lazarus and Folkman (1984) emphasised the role of appraisals of stress (e.g., an individual's perception of the significance of what is happening for their own wellbeing) and coping (e.g., an individual's effort to manage demands). Petalas et al. (2009) applied aspects of this theory to their findings and reasoned that siblings' personal accounts and perceptions of their brother with autism may be associated with their appraisal process and linked to their coping response.

Research on the ability of typical siblings to cope with stressors and demands has been relatively neglected in the literature and may account for variability in adjustment outcomes (Ross & Cuskelly, 2006). The authors described that an extensive body of work has been dedicated to the study of inter-parental coping and adaptation in families where a child has a disability (McCubbin & Patterson, 1983; Donovan, 1988; Wikler, 1986). However, significantly less research has investigated how typical siblings of children and young people with disabilities cope and adapt to stress and demands.

Hastings (2003b) demonstrated that effective social support can act as a protective factor against the negative impact of family stress on siblings of children and young people with autism.

Cummings, Greene and Karraker (1991) suggested that coping is defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing" (p. 92). Lazarus and Folkman (1984) also defined coping as "exceeding the resources of the person" (p.141).

Coping in essence reflects an active attempt to reduce interpersonal problems and difficulties and reflects a conscious attempt to master, minimise or tolerate stress (Zeidner & Endler, 1996; Snyder, 1999; Weiten, & Lloyd, 2008). Carver and Conner (2010) proposed that there is a degree of variability between individuals in terms of their coping responses to stressors. The authors suggested that the coping responses individuals adopt can be determined partially by personality factors, but also by the social context and nature of the environment.

A range of coping responses has been identified in the literature. Weiten and Lloyd (2008) suggested these coping responses can be grouped into three broad types of responses:

- appraisal focused (adaptive cognitive);

- problem focused (adaptive behavioural); and

- emotion focused.

Weiten and Lloyd (2008) indicated that appraisal focused coping strategies occur when an individual attempts to alter the way they think, such as employing denial. The authors suggested problem focused coping responses occur when individuals attempt to deal proactively with their situation, such as expanding their knowledge and understanding or learning new skills in an effort to reduce or change the source of stress. Brougham, Zail, Mendoza and Miller (2009) suggested problem focused coping strategies result in improved physical health and wellbeing, as well as improvements in self-esteem.

Brannon and Feist (2009) proposed emotion focused coping strategies are "oriented toward managing the emotions that accompany the perception of stress" (p. 121). Emotion focused coping strategies reflect an active attempt to manage hostile and difficult emotions, such as distraction, or mediating to reduce feelings of emotional instability. Lazarus and Folkman (1984) identified several emotion focused strategies (e.g., disclaiming, escape-avoidance, accepting responsibility/blame, exercising self-control, seeking social support and positive reappraisal).

The majority of individuals use a combination of these coping strategies. These strategies are flexible and adaptive in response to specific stressors and demands and change over time.

Taylor (2006) reported that problem focused strategies may empower an individual and allow greater perceived control over stressors. The author also proposes that emotion focused coping may lead to maladaptive coping and adjustment. Also, the individual may experience a reduction in perceived control.

Davis, Matthews and Twamley (1999) described that stress is frequently implicated in models of illness and disease. Maladaptive coping strategies are highly significant. Research suggests that individuals placed in extremely stressful situations exhibit cognitive deficits, physical illness, increased levels of internalising adjustment difficulties (e.g., anxiety and depression), poor self concept and sleep disturbances (Brougham et al., 2009).

Gamble and McHale (1989) conducted one of the first studies that investigated stress, coping and adjustment outcomes in typical siblings of children with a variety of disabilities. The authors explored child perceptions of the frequency of stressful events, cognitive appraisals linked to stressors and subsequent coping responses. Cognitive appraisals were categorised into four distinct subtypes: environment directed cognition, self directed cognition, environment directed behaviour and self directed behaviour. Siblings of children with a disability were found to use 'other directed' cognitions (e.g., blaming others) more frequently to cope with stress resulting from difficulties with their disabled sibling. The authors suggested 'other directed' coping responses are

associated with more negative adjustment outcomes. Furthermore, typical siblings of children with a disability were found to be more poorly adjusted in comparison to typical sibling participants. The authors demonstrated that 'self directed' cognitions (e.g., relaxation/calming strategies) were negatively associated with depression and anxiety.

Roeyers and Mycke (1995) carried out the only study to date which focused on sibling coping in a sample of typical siblings of children with autism. The authors duplicated some elements of the study conducted by Gamble and McHale (1989). They had three distinct experimental groups (e.g., typical siblings of children with autism, intellectual disability and typical sibling dyads). Their findings supported the work of Gamble and McHale (1989). The authors demonstrated that siblings of children with autism frequently use 'other directed' cognitions to cope with stressors.

VanRiper (2000) demonstrated that effective family coping and problem-solving capacities have been correlated with increased social competence in siblings of children with Down's syndrome.

In summary, the literature indicates that a broad range of variables at different levels account for the variance in typical siblings' perceptions of the quality of the inter-sibling relationship and typical sibling adjustment. Stoneman (2005) reviewed research on factors that explain this variance and developed a model, underpinned by ecological systems theory (Figure 2):

Figure 2: Variables that impact on inter-sibling relationships of children and young people with a disability (adapted from Stoneman, 2005).

Stoneman's model demonstrated the range of variables that interact and impact on the inter-sibling relationship, across different systems, when a child or young person has a disability (e.g., differential parenting, stress, coping resources). These variables are proposed to account for variance in typical siblings' perceptions of inter-sibling relationship quality, typical sibling adjustment, intra-familial relationship quality and global family functioning. Issues and factors closer to the centre of the model are considered to be more proximal to the sibling relationship, whilst distal factors and influences are considered to be less relevant. Stoneman (2005) suggested these variables may support healthy adjustment (e.g., family support programmes) or have a

deleterious impact on adjustment (e.g., differential parenting) for typical siblings of children and young people with disabilities, such as autism.

2.7   Discounting pathology models

The disability literature has been reviewed and related to typical siblings of children with autism. The majority of the research in this field has been conducted over the past two decades, from a clinical perspective. Many of these studies have been underpinned by deficit models, in line with a pathology perspective or personal tragedy theory. Moore (2008) suggested this deficit model viewed disability from an individual-deficit perspective. This has perpetuated "the notion that a family with a child with a disability is a family with a disability" (Glidden, 1993, p.482).

Turnbull and Turnbull (2003) proposed that a deficit perspective considers that those with disabilities should adapt to 'norms' by developing the skills and learning behaviours to compensate for areas of deficit. The authors suggested that for many years, research designs have focused more on inconsistent measurement of clinically significant adjustment negative outcomes for typical siblings. This has resulted in an imbalance in the literature.

More recently, researchers have began to address this issue (e.g., Mascha and Boucher, 2006; Bachraz and Grace, 2009; Petalas et al., 2009). The authors were guided by a social model of disability in order to account for the imbalance in the literature. Many of these studies have been underpinned by systems perspectives (e.g., Stoneman, 2005). These designs and theoretical

frameworks have enabled researchers to more accurately harness the voices of typical siblings of children and young people with autism (e.g., Dellve et al., 2000; Mascha & Boucher, 2006; Benderix & Sivberg, 2007; Petalas et al., 2009). Findings from these studies have challenged deficit perspectives and pathology models and demonstrated that positive outcomes can result from having a sibling with a disability, such as autism. These studies have also demonstrated the methodological and conceptual complexities of research in this area (Hodapp et al., 2005; Stoneman, 1993, 2005).

Bachraz and Grace (2009) suggested that this shift in the theoretical foundations in the disability literature is "a welcome shift from the dominant assumption that having a sibling with a disability is always going to be unfortunate" (p.318).

2.8   A new brand of research?

More recently a number of authors have employed qualitative designs in an attempt to discount pathology models and address the complex research questions that have emerged in the disability literature.

Bagenholm and Gillberg (1991) conducted interviews with twenty siblings of children with autism, twenty siblings of children with intellectual disability and twenty siblings of typically developing children between the ages of five and twenty years. A semi-structured interview was used to explore typical siblings' self-constructs, inter-sibling relationship quality and the perceptions of their sibling. All siblings expressed positive views about their brother or sister across

the three groups. In some cases siblings of children with autism were more negative about their relationship with their brother or sister, reported increased problems and difficulties with their siblings' behaviour and appeared more concerned about the future. Siblings of individuals with autism also reported feeling lonelier in comparison to siblings of children and young people with intellectual disability and typically developing controls.

Dellve et al. (2000) conducted a qualitative study with typical siblings of children with deficits in attention, motor control and perception (DAMP) and Asperger's syndrome. The aim of this study was to provide typical siblings with the opportunity to describe, from their own perspectives and experiences, how they cope with their life situations in their families. Fifteen adolescent females (aged twelve-eighteen years), eight typical siblings of boys with DAMP and seven typical siblings of children with Asperger's syndrome were interviewed. The authors used grounded theory to analyse the interview data and two core concepts emerged from the data. The first concept was associated with typical siblings' life situations in DAMP and Asperger's syndrome (e.g., dilemma of requirements and concerns). The second concept was associated with typical siblings' coping processes. Out of the six categories identified, four were categories of the processes of coping (e.g., gaining understanding, gaining independence, following a bonding responsibility and balancing). The authors suggest these findings contribute to a deeper understanding of typical siblings' life situations, and may be important for those supporting typical siblings and in the identification of SEN. The authors also suggest that the findings may also support the development of support services for typical siblings of children

with DAMP and Asperger's syndrome. This initial qualitative evidence is limited in that is not directly generalisable to typical siblings of children with autism. This is significant, because as previously mentioned autism has its own unique aetiology, which may impact on typical siblings in specific ways. Furthermore, the authors failed to account for extraneous variables, such as gender, birth order, and typical sibling age between groups.

Mascha and Boucher (2006) conducted a qualitative investigation into the positive and negative effects of having a sibling with autism or ASD. The sample consisted of 14 children (*m = 10; f = 4)* ranging from eleven to eighteen years. A semi-structured interview format was employed to explore the family situation and typical siblings' perceptions of their brother or sister. Interviews were subsequently transcribed and subjected to content analysis. Typical siblings spoke about difficulties they encountered, with the most frequent difficulty being their sibling's aggression, anger and mood swings. Typical siblings also described feelings of embarrassment caused by certain behaviours and social stigma. An additional category emerged concerning typical siblings' need to explain the nature of their siblings' difficulties to other people, especially when the sibling with autism appeared 'normal'. Some typical siblings also described the burden of heightened responsibility for caring for their sibling in order to support parents. This research also captured siblings' positive perceptions and typical siblings described how they shared a good natured relationship with their sibling. Some typical siblings also described how they enjoyed engaging in play activities with their sibling with autism. Typical siblings described feeling anxious about their sibling's welfare and impairments in development (e.g.,

regression in language development). Around half of the participants were concerned about what the future held and about their own responsibilities for their sibling with autism in future years. The authors indicated that the main implication for their findings was associated with the value of identifying positive aspects of having a sibling with autism or ASD, as well as negative aspects. The authors supported the conclusions of Moes and Frea (2002), who suggested that in order to support typical siblings, attention needs to be directed to the overall family circumstances when assessing needs and planning interventions. These initial findings present interesting evidence that could potentially be extremely beneficial in the identification of risk and protective factors. However, the authors used a relatively small sample of participants, with a male gender bias. Furthermore, the authors used a homogenous group of siblings with ASD and autism.

Benderix and Sivberg (2007) described the present and past experiences of fourteen siblings from five families with sibling with autism and mental retardation. Personal interviews were conducted with typical siblings before the young person with autism was moved to a group home. Qualitative content analysis was employed and seven themes emerged from the data:

- precocious responsibility;
- feeling sorry;
- exposed to frightening behaviour;
- empathetic feelings;
- hoping that a group home will be a relief;

- physical violence made siblings feel unsafe and anxious; and

- relations with friends were affected negatively.

The authors concluded that typical siblings experienced stressful life events as a consequence of living in a family with a young person with autism and intellectual disability. The authors suggested that typical siblings would benefit from counselling and that group homes reflected an alternative to temporary or permanent placement. Further to this the authors emphasised the role of pedagogical support and early intervention. These initial qualitative findings presented novel themes. However, this study was limited in that it was relatively small in scope and included a sample of only fourteen siblings from five families. In addition to this the authors failed to account for the developmental stage of typical siblings and the participants ranged from five to twenty nine years. Other variables (e.g., birth order, family size) were considered, but not controlled for. Many of the questions in the interviews were also closed and leading (e.g., does he/she do things that you don't like?). The authors also failed to address issues around reliability and validity in their methodology.

Ross and Cuskelly (2006) also explored the experiences and feelings of typical siblings of children with ASD, with an emphasis on dynamic variables in a mixed methods design. The authors reasoned that an investigation of dynamic variables could be more beneficial in reducing the impact on typical siblings, in comparison with research concerned with status variables (e.g., birth order). This study explored the impact of coping skills and knowledge of ASD on the

adjustment of typical siblings. The participants in the study comprised twenty-five typically developing siblings of children and young people with autism and twenty-five typically developing children and young people. The authors found that other-directed cognitions and attributions of responsibility resulted in more negative adjustment outcomes. The authors described that these results were more likely in children and young people who had limited knowledge of autism and a poor understanding of their siblings condition in replication of previous research (e.g., Roeyers & Mycke, 1995). Furthermore, siblings with more knowledge of ASD had more positive relationships with their sibling. These results present new evidence as well as generating support for previous findings in the literature. However, the results should be treated with caution as there was a gender bias in the sample (*m=19; f= 6).* The age range of participants spanned mid-childhood to adolescence (6-16) and the size of the sample was small. Furthermore, families were volunteers, thus leading to a bias in the research as certain families/individuals may be more likely to volunteer to participate . These factors limit the generalisability of the findings.

Bachraz and Grace (2009) explored the nature of sibling relationships when one child in the family has autism. A collective case study approach was used to capture the perspectives of parents and young children aged four to seven years from three families. The authors conducted in-depth interviews with children and parents, as well as naturalistic observations. Family systems theory and ecological systems theory underpinned this research. The findings suggested that issues such as differential treatment of typical siblings and the development of a non-typical sibling relationship had an impact on typical

siblings' perceptions of the quality of the inter-sibling relationship. However, the findings must be interpreted with a degree of caution. The researchers failed to include older typical siblings, as well as controlling for other variables, such as child age, child gender and birth order.

Petalas et al. (2009) used semi-structure interviews to explore the perceptions and experiences of eight typically developing siblings in middle childhood. The interviews were analysed using interpretive phenomenological analysis (IPA). All siblings identified positive aspects of having a brother with autism, albeit to varying extents. The research demonstrated siblings' divergent attitudes and perceptions. Some siblings expressed positive attitudes, whereas others expressed a desire for change. The following themes emerged from the data:

- siblings' perceptions of the impact of their brother's condition on their lives;

- siblings' perceptions of the attitudes of others;

- siblings' tolerance and acceptance toward their brothers;

- positive attitudes and experiences; and

- siblings' views on support for support for themselves and their brothers.

Petalas et al. (2009) identified five themes which have implications for practice and may be helpful in informing future research. However, the findings should be interpreted with caution. The sample of participants was small. Also the researchers included typical siblings of children with ASD, Asperger's syndrome and attention deficit hyperactivity disorder (ADHD).

2.9   Concluding remarks

As the disability literature has developed and investigations have been extended beyond the parent-child/inter-parental subsystem a number of methodological criticisms have emerged in the literature. Stoneman (1993, 2005) posited that despite this increase in research, the sibling disability literature has experienced 'scientific inertia' as researchers "continue to study what has been studied in the past, using methods and measurements that have been used before" (p. 344). The author criticised the fact that conceptual frameworks and research methods have failed to evolve over time, which hindered the development of a conceptual understanding.

Despite extensive work in this complex field, research remains underdeveloped (Hodapp et al., 2005). A number of inconsistencies permeate the literature, which makes it challenging to draw accurate conclusions in relation to the adjustment of typical siblings of children with autism (Petalas et al., 2009).

Hodapp et al. (2005) conducted an analysis of twelve articles in the literature, published between 1997 and 2008. These articles related to the social, emotional and behavioural adjustment of individuals of siblings with autism spectrum disorder and Hodapp et al. identified six themes relating to the challenge of conducting research in this field. The authors suggest that previous studies on typical siblings' of children with disabilities have typically used small samples of participants, which typically consist of twenty to fifty participants per group. Also, the authors suggest that a range of variables (e.g., sibling age, age spacing, birth order, sibling gender) are rarely taken into account in

research designs (e.g., Begum & Blatcher, 2011). Hodapp et al. (2005) described that research designs have also included families with more than one disabled sibling. This has significant implications as the authors suggest these findings may be difficult to generalise to other families with different characteristics. The unique demographic characteristics of families clearly need to be considered when developing designs (e.g., McHale et al., 1986; Orsmond & Seltzer, 2000).

Hodapp et al. (2005) criticised the recruitment methods that have been used in research in this field. Participants have often been recruited from clinics, hospitals and support groups. Rowitz (1993) suggested that participants recruited from these settings may differ in terms of demographic characteristics (e.g., socioeconomic status) in comparison to participants who may be less involved and be most in need. Less involved families may be most in need of support services. Research should attempt to incorporate samples of participants that are representative of the parent population to develop a more accurate conceptual understanding.

The authors also criticise measurement techniques employed in the research, such as the SRQ (Furman & Buhrmester, 1985). The SRQ has been used in a number of studies in the disability literature (e.g., Bischoff & Tingstrom, 1991; Fisman et al., 1996; Lardieri, Blatcher, & Swanson, 2000; Kaminski & Dewey, 2001; Floyd, Purcell, Richardson, Kupersmidt, & Abbeduto, 2009). In recent research other factors, such as knowledge of autism (Glasberg, 2000; Howlin, et al., 2002; Harris & Glasberg, 2003), spending time together (Lobato et al., 1991; Knott et al., 1995; Heller et al., 1999), caretaking responsibilities and role

demands (Stoneman et al., 1991; Coleby, 1995; Cuskelly & Gunn, 2003; Stoneman, 2005), family climate (Dallas et al., 1993; Howell et al., 2007) and differential parenting and attention (Lobato et al., 1991; Corter et al., 1992; McHale & Pawletko, 1992; Fisman et al., 2000; Ellison & Freeman, 1998; Stoneman, 1998, 2005) have been found to impact on perceptions of inter-sibling relationship quality when a child or young person has autism. Hodapp et al. (2005) criticise the use of the SRQ and conclude that "such issues are rarely tapped by the most commonly used sibling measures" (p. 336).

Hodapp et al. (2005) also criticised the fact that research on typical siblings of children with disabilities has failed to investigate the role of mediating and moderating variables (e.g., based on gender, ethnicity, culture, birth order). The authors suggests the role of these variables is still not comprehensively understood.

Hodapp et al. (2005) suggested that "sibling researchers have paid insufficient attention to control or contrast groups" (p.335). The authors describe that many research designs have no matched control groups to enable accurate comparisons to be drawn. Some research designs have used comparison groups of siblings of children with a range of disabilities (e.g., Wolf et al., 1998; Kaminski & Dewey, 2001, 2002; Pilowsky et al., 2004) or normative data from typical sibling dyads (e.g., Mates, 1990; Bagenholm & Gillberg, 1991; Rodrigue et al., 1993; Kaminski & Dewey, 2002; Hastings, 2003a; Ross & Cuskelly, 2006). This has implications for the representativeness of samples and the generalisability of the findings. There are unique aetiological differences between disabilities, particularly as a result of specific genetic factors, which may impact on typical

siblings and families in very different ways. Petalas et al. (2009) proposed "to fully explore the emotional and behavioural adjustment of siblings of children with autism it is important to make comparisons with both a suitable comparison and a normative sample" (p. 473).

Orsmond and Seltzer (2009) suggested that "the research on siblings of children with autism has not generally taken life stage into account" (p.1053). The authors suggest that the vast majority of research has included children from early childhood and adolescence in the same sample (e.g., Mates, 1990; Bagenholm & Gillberg, 1991; Gold, 1993; Royers & Mycke, 1995; Kaminski & Dewey, 2002). As children progress into adolescence, families may be confronted with new challenges as a result of this developmental stage and sibling relationships change throughout development (e.g., Buhrmester & Furman, 1990; Brody et al., 1994a; Cole & Kerns, 2001; McHale et al., 2006). It is clear that the developmental stage of both the typical sibling, as well as the sibling with the disability needs to be considered.

Qualitative small scale research designs (e.g., Benderix & Sivberg, 2007; Bachraz & Grace, 2009; Petalas et al., 2009) have attempted to further research in the field through exploratory research paradigms. However, researchers have experienced difficulty addressing the variability both within and between groups of participants. Samples are typically small and the role of extraneous/constellation variables are rarely acknowledged. Issues relating to validity and reliability are rarely applied to methods of measurement (e.g., semi-structured interviews). Researchers also rarely fail to account for

developmental stage and heterogonous groupings of children with a range of disabilities are sometimes used.

As a result of the fact that a standardised measurement tool has not yet been developed to assess the quality of the inter-sibling relationship of typical siblings of children with autism, a decision was taken to employ a qualitative research design in the current research.

As a result of the discrepancies in the findings in the literature, a decision was taken to adopt an open ended approach. This approach will be guided by a family systems theory and ecological systems theory. These theoretical foundations will direct the research agenda away from deficit/pathology models. This theoretical approach will also aim to develop a more comprehensive understanding of the issues that impact on typical siblings of young people with autism and the voice of the child will be central throughout the research process.

The current research will address the previous methodological criticisms outlined by a range of authors (e.g., Hodapp et al., 2005; Petalas et al., 2009; Begum & Blatcher, 2011) in order to develop a more rigorous methodological approach.

The current research will explore the constructions, perceptions and coping responses of typical siblings of young people with autism and makes a valuable contribution to the existing research in this area for the following reasons:

- it is one of the first open-ended exploratory studies in the field to examine the role of typical siblings' constructions and coping responses;

- it will address methodological issues and acknowledge the role of constellation variables (e.g., sibling gender, homogenous groups, birth order);

- the study will be guided by both ecological systems theory and family systems theory;

- the study will briefly explore typical siblings'' constructions and perceptions of support; and

- the study will harness the voices of typical siblings of children with autism in an exploratory paradigm to inform the development of a model that accounts for variability in typical siblings' perceptions, constructions and coping responses.

As previously discussed, typical siblings' perceptions, constructions and coping responses form part of their appraisal process, which has important implications for adjustment outcomes (Stoneman, 2005; Petalas et al., 2009). This research is of relevance to the practice of EPs as they may be called upon to provide services and support to families of children with autism. It is important that practitioners are aware of the many ways in which typical siblings of children with autism are affected as a function of the unique challenges presented by autism and the BAP. It is crucial that research contributes to a conceptual awareness of the factors that contribute to variability between families, in order to inform intervention and support services.

Chapter Three

Methodology

This chapter provides details of the methodology selected. The epistemological basis for the research is outlined and justified. The chosen research paradigm is described and subjected to critical evaluation. Information about the recruitment of participants is supplied. Data collection procedures are outlined and the method of measurement (e.g., semi-structured interviews) is described and critically evaluated. The method of data analysis is justified and the procedure is outlined. Issues relating to validity and reliability are discussed. Details about ethical arrangements for the research are also provided.

3.1 Epistemology

A qualitative approach was selected in order to address the research question and explore typical siblings' constructions, perceptions and coping responses in an exploratory paradigm. A qualitative approach was selected as a means of exploring and gathering experiential information from typical sibling participants. It was felt that this approach would enable a rich and comprehensive understanding of typical siblings' constructions to emerge. Thematic analysis was chosen as opposed to a quantitative method of data analysis. This decision was taken as the research is exploratory, naturalistic and inductive. Furthermore, the sample size was too small to have enabled appropriate quantitative analysis (e.g., non-parametric hypotheses testing), as

statistical power would have been an issue. The research was also not concerned with the testing of pre-determined hypotheses, which in some cases can be viewed as 'deductive' and 'reductive'.

Braun and Clarke (2006) assert that qualitative research methods such as thematic analysis can be "conducted within both realist/essentialist and constructionist paradigms, although the outcome and focus will be different for each" (p.85). The decision was taken to ascribe to a constructionist epistemological position to guide the research for several reasons.

Firstly, a constructionist position enables an exploration of discourse and acknowledges the role of socio-cultural factors in contributing to discourse (Burr, 2003). This is relevant as issues associated with typical siblings' constructions of specific issues (e.g., embarrassment, social stigma, knowledge and understanding of autism) may be pertinent. This epistemological position also acknowledges that different individuals co-construct concepts in different ways. Broad concepts, such as 'disability' and more narrow concepts, such as 'autism' reflect social constructs. This is significant as these concepts may mean different things to different individuals based on individual constructions of their unique realities. These constructs may also change as a function of time and development. Also, the severity and presentation of autism varies significantly between individuals and this epistemological position will enable this to be reflected in the research. This concept is supported by Albrecht and Levy (1981), who propose that "despite the objective reality, what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments." (p. 14).

Secondly, this position accepts that constructs are created on the basis of social processes and interactions; they do not reflect absolute truths (Burr, 2003), in contrast to essential/realist positions. Constructs will therefore vary on the basis of experiences and discourse which shapes the constructs and categories we create and respond to.

Finally, this perspective was chosen as it acknowledges that researchers also construct their own reality and meaning which may limit the extent to which they are able to remain objective.

A more detailed account of the epistemological position of the research is contained in the 'data analysis' section, which outlines and justifies the method of qualitative analysis used in the current research.

3.2   Recruitment procedures

In the first instance seventy two gatekeepers (headteachers, ASD Coordinators in local education authorities (LEAs) and voluntary organisations) were contacted. Gatekeepers were informed about the research and invited to participate in writing. Gatekeepers across twelve local authorities across South Wales and the West Midlands were contacted. These locations were selected as they are considered to be varied demographically and for logistical reasons. Gatekeepers were informed about the research and provided with information about the inclusion criteria. Male and female typical siblings (aged 8 to 20 years) residing in South Wales/West Midlands were invited to participate in the research. Typical siblings were required to have an adolescent brother (aged

13-19 years) with a formal diagnosis of autism residing permanently in the family home. Typical siblings were excluded from participating in the research if their brother had a diagnosis of any other disorder (e.g., ADHD) or disability. This decision was taken in order to strengthen the generalisability of the findings. In addition to this the families were only included in the research if they had one child in the family with autism and if they had a maximum of three children. Single parent and two parent families were invited to participate in the research.

In order for the sample of participants to be representative of the parent population a number of decisions were taken. These decisions were taken to ensure that findings can ultimately be generalised to inform large scale studies in the future. Previous research in the field has been subject to criticism as a result of the fact that samples of participants have been recruited from a single source (e.g., parent support groups). This creates a bias and will subsequently limit the extent to which the findings are generalisable to the parent population.

Coon and Mitterer (2008) described that "a very important aspect of representative samples is that their members are chosen at random" (p.605). Therefore, in order to ensure the sample of participants were representative of the parent population a random sampling procedure was employed. This is significant as every family had an equal chance of being chosen to participate in the research. A list of the thirty six families who met the inclusion criteria and were willing to participate was constructed. Each participant's full name was

recorded on a piece of paper and then chosen at random. A total of thirteen participants were selected at random.

3.3   Measurement

A number of types of interview have been described in qualitative research (Patton, 1980; Lincoln & Guba, 1985; Bogdan & Bilken, 1992; Oppenheim, 1992; LeCompt & Preissle, 1993, cited in Cohen, Manion & Morrison, 2007) and there are a number of options to choose from:

- standardised interviews;

- in-depth interviews;

- ethnographic interviews;

- elite interviews;

- life history interviews;

- focus groups;

- semi-structured interviews; and

- exploratory interviews.

Kvale (1996, cited in Cohen et al., 2007) considered these types of interviews and argues that "Interviews differ in the openness of their purpose, their degree of structure, the extent to which they are exploratory, arguing that interviews differ in their openness of their purpose, their degree of structure, the extent to which they are exploratory or hypothesis testing, whether they

seek description or interpretation, or whether they are largely cognitive-focused or emotion focused" (p.345). These guidelines were considered and as a result a semi-structured interview format was selected to address the research question.

Standardised interviews would have been considered. However, no standardised interview tools exist and research in this area is still in its infancy (Cuskelly, 1999, 2005; Petalas et al., 2009). Also, a standardised interview (e.g., questionnaire) may have guided participants' responses and would have limited the open-ended nature of the questions. The semi-structured interview offered the opportunity to explore participants' constructions, perceptions and coping responses in a 'non-directive' manner. This approach enabled the researcher to retain a degree of control and consistency in questioning between participants, whilst allowing the participants to direct and control discourse and dialogue. This may have empowered the participants and provided them with the opportunity to digress and focus on issues that were meaningful to them.

Focus groups were considered. However, as a result of individual differences in the presentation and severity of autism it was felt that group process may impact on participants' responses and polarise opinions. It was also considered more practical to overcome logistical issues (e.g., organising for participants to travel from a large geographical area). Focus groups would have also been difficult to coordinate and were considered impractical due to the scope and purpose of the research. Focus groups are also limited as they present a threat to individual confidentiality. It can be challenging to retain accuracy when

transcribing focus group data, particularly in larger groups. Due to the scope of the research and the fact that only one researcher was involved, it would have been challenging to coordinate and conduct observations in a focus group.

Opdenakker (2006) described that face-to-face interviews have been most commonly used in qualitative research. However, the author emphasises that there are other channels through which qualitative research can be conducted (e.g., telephone interviewing, computer mediated communication). In the current research, face-to-face interview channels were considered appropriate as they are characterised by 'synchronous information' in space and time, such as social cues (Opdenakker, 2006). A face-to-face interview method enabled the researcher to document verbal and non-verbal communication. This method was also helpful in building rapport. The issue of rapport and dynamics in communication was considered throughout this phase of the research, given the target population for the research. Time was taken to ensure participants were comfortable and able to express their responses in a non-judgemental, person-centred interaction. Principles from motivational interviewing (Miller & Rollnick, 1991) were adopted during the interviews (e.g., open-ended questions, affirmations, reflections, paraphrasing, summarising). These principles were adopted to empower participants and to develop rapport and facilitate exploration of constructs that were meaningful to participants. Also, face-to-face semi-structured interviews enabled the researcher to check out the participants' understanding of the questions being asked and clarify their thinking.

Semi-structured qualitative research emphasises the role of 'reflexivity' and language in the construction of meaning, which was well suited to the research agenda. The researcher has extensive experience in the use of semi-structured interviews in qualitative research which aided this process.

Despite its many advantages, the use of semi-structured interviews in qualitative research has a number of disadvantages, which were considered during the conceptualisation of the research. Firstly, the lack of a standardised approach requires a degree of skill and experience on the part of the interviewer and this raises additional questions about the reliability of this approach. Secondly, this approach can be time consuming and costly, particularly when conducting research in a large geographical area or with a large sample of participants. Robson (1993) posited that interviews that exceed one hour can be demanding for participants, whilst interviews lasting less than thirty minutes can be limited in the wealth of information and data they offer.

Open-ended semi-structured interviews were employed as the method of data collection in the research. This enabled the researcher to focus on issues that were meaningful to each participant (Barbour, 2000).

This method of data collection fits with a constructionist perspective, as illustrated by Cohen et al. (2007), who comment that "Interviews enable participants- be they interviewers or interviewees-to discuss their interpretations of the world in which they live, and to express how they regard situations from their own point of view. In these senses the interview is not simply concerned with collecting data about life: it is part of life itself, its

human embeddedness is inescapable" (p.349). In addition to supporting the epistemological basis for the research, this method of data collection enabled a degree of exploration, without the constraints of predetermined categories.

The design of the semi-structured interview was informed by the theoretical basis for the research (e.g., family systems theory and ecological systems theory). This provided the opportunity to explore how variables across different systems interact and impact on typical siblings. Interview formats and methodologies from previous qualitative studies (e.g., Harris & Glasberg, 2003; Stoneman, 2005; Benderix & Sivberg, 2007; Petalas et al., 2009), were also used to inform the design of the semi-structured interview. Some questions from the semi-structured interview have been used in previous studies. Some questions were adapted and additional questions were added to inform the research. As the semi-structured interview was constructed for the purpose of the current research and had not previously been used with participants, a pilot phase was considered crucial. From the thirteen families, one family was selected on a random basis and this constituted the 'pilot family'. The semi-structured interview was piloted with the typical sibling participant from 'pilot family'. The typical sibling was female and sixteen years of age. She came from a two parent family and had a younger brother (age fourteen) with a formal diagnosis of autism. The pilot phase was conducted in a quiet room in the home of the typical sibling participants. All aspects of the procedure were followed. The original semi-structured interview format (Appendix One) was used during the pilot phase. The participant was asked to provide verbal feedback following the pilot phase and there was a discussion about each question following the semi-

structured interview. The participant was asked if any questions could be changed or omitted, with a view to making the semi-structured interview format more accessible for all participants. The participant commented that a number of the questions were repetitive, which was reflected in her responses. Following observations during the pilot phase and feedback from the typical sibling, some amendments were made and some questions were omitted. This decision was taken as some questions were leading, closed and repetitive. Also, some of the language was adapted to reduce complexity. Questions were also grouped together and this made the semi-structured interview more open ended and reduced the time it took to conduct the interview. A shorter and more accessible semi-structured interview was created in response to the information, observations and feedback from the pilot phase (Appendix Two).

3.4   Validity and reliability

Patton (2001) suggested that qualitative researchers should consider the concepts of validity and reliability when designing a study, analysing data and judging the quality of a study. Golafshani (2003) asserts that "the concept of validity is described by a wide range of terms in qualitative studies" (p.602). The author also proposed that the concept of validity is not a universally fixed construct in qualitative research and that the concept is dependent on the researcher's perception of 'validity', which is likely to be guided by the assumptions associated with the research paradigm. Winter (2000) supports this assertion and posits that validity is a "contingent construct, inescapably

grounded in the processes and intentions of particular research methodologies and projects" (p.1). Golafshani (2003) described that some qualitative researchers consider that 'validity' is not applicable to qualitative research. However, in the current research reasonable attempts were made to ensure the validity was maximised. Many qualitative researchers have reconstructed the concept of validity as 'quality', 'rigour' and 'trustworthiness' (Lincoln & Guba, 1985; Seale, 1999; Mishler, 2000; Stenbacka, 2001; Davis & Dodd, 2002). These concepts were considered paramount throughout the research to demonstrate rigour and to ultimately enhance the generalisability of the findings.

Barbour (2001) advocated the use of checklists in qualitative research and other authors assert that checklists can be integral in demonstrating that a rigorous and systematic approach has been applied throughout the research process (Hoddinott & Pill, 1997; Seale & Silverman, 1997; Popay, Williams & Rogers, 1998). In the current research a checklist was developed to improve rigour and to remind the researcher of the stages involved in the research design and data analysis. Aspects of this questionnaire were informed by principles outlined by Cohen et al. (2007) and Braun and Clarke (2006). However, this checklist was flexible and retained the exploratory nature of the research.

Holloway and Wheeler (2002) have criticised methods of data analysis, such as grounded theory and IPA. The authors suggest that researchers need to identify a research question in order to improve rigour in qualitative research. In the

current research the exploratory research question was informed by the literature and identified at the outset.

Consideration was given to the method of coding to demonstrate and improve rigour in the current research, which has been advocated by Barbour (2001). Codes were ascribed using an alpha-numerical coding system and were then grouped into broad themes. This coding method was consistent across the data set. An independent EP, with a background in qualitative research and a special interest in autism, cross-checked the codes ascribed across the data set to improve rigour and reduce subjectivity.

Barbour (2001) asserted that respondent validation is frequently used in qualitative research. The author suggested that this process involves checking and clarifying findings with participants, which can refine understanding and improve rigour. The structure of the current research was open-ended and thus flexible in its nature. This enabled the researcher to use open questions to explore participants' constructs in greater depth in order to clarify the researcher's understanding.

A triangulation approach can contribute to a more rigorous analysis of qualitative data. Patton (2001) asserted that "triangulation strengthens a study by combining methods. This can mean using several kinds of methods or data, including using both qualitative and quantitative approaches" (p.247).

A triangulation approach was not adopted in the current research. This decision was taken as a result of the inconsistencies in the quantitative research in the literature. Also, a triangulation approach was considered beyond the scope of

the research. It was felt more appropriate to explore typical siblings' constructions in greater depth in order to inform the research question.

Lincoln and Guba (1985, p. 300, cited in Golafshani, 2003) proposed that "dependability" in qualitative research is closely associated with the notion of "reliability" in quantitative research. Lincoln and Guba (1985) advocate the use of "inquiry audit" (p.317) to improve dependability and to examine both the process and data generated from qualitative research to improve consistency.

To enhance dependability, several steps were taken. Campbell (1996) suggested that consistency can be achieved when each step of data analysis is verified. The author proposed that this can be achieved through the examination of raw data, data reduction products and process notes. In the current research raw data were examined closely during the transcription phase. Notes relating to emerging themes were made across the data set in conjunction with guidance outlined by Braun and Clarke (2006). The coding process enabled data to be reduced to reflect key constructs. As previously mentioned a double-coding method was also adopted. Miles and Huberman (1994) asserted that double-coding is a method of checking reliability during the data analysis phase in qualitative research. In the current study two researchers coded the data and inter-coder reliability was calculated. The inter-coder reliability coefficient was calculated on the basis of percent agreement (Neuendorf, 2002):

$$PA_o = \frac{2A}{(n_1 + n_2)}$$

A transcript that had been subjected to analysis was selected at random. The inter-coder reliability was calculated:

$$\text{Inter-coder reliability} = \frac{47}{50 + 3}$$

The reliability coefficient was calculated for the individual transcript (88%). Miles and Huberman (1994) asserted that most researchers aim to achieve a percent agreement coefficient as close to 90% as possible. Krippendorff (1980) asserts that coefficients above 80% are good and coefficients between 67% and 79% are acceptable. Riffe, Lacy and Fico (1998) argued that percent agreement coefficients below 70% threaten the reliability of inter-coder agreement. As the percent agreement coefficient in the current research was 88% for one transcript it is fair to conclude that there was a good degree of inter-coder agreement between the researcher and the independent EP.

3.4   Procedure

Gatekeepers were initially contacted in writing and were informed about the research (Appendix Three). Gatekeepers were told that they would be contacted by telephone on a specific date to discuss the research in more depth. A opt out form was included, with a stamped addressed envelope. This provided gatekeepers with the opportunity to choose not to participate in the research. Gatekeepers were required to return the opt out forms by a specific

date. A list of gatekeepers who opted out of the research was generated and no further contact was made. Another list of gatekeepers who did not return the opt out forms was compiled. These gatekeepers were then contacted by phone to discuss the research in more depth. Gatekeepers were required to complete consent forms (Appendix Four) and estimate the total number of families who met the inclusion criteria. A total of forty eight families were eligible to participate in the research and information about the research, consent forms and opt out forms were sent to gatekeepers. The gatekeepers subsequently distributed research packs and information to parents of children and young people who met the inclusion criteria (Appendix Five).

Parents were required to complete a consent form and opt-in form if their typical child or young person was willing to participate in the research, which was included in the research pack. Consideration was given to the treatment and storage of this information and this was outlined in the debriefing forms to parents (Appendix Six). Parents were invited to complete consent forms and opt-in forms and return this information in a stamped addressed envelope by a specific date. After this cut off date thirty six families consented to be involved and nine families chose to opt out of the research. Six families reported this was due to the fact that they had other commitments at the time when the research was due to be conducted. Three families provided no reasons for opting out. A list of the thirty six families was collated and a sample was selected using a random sampling procedure, as previously discussed. A total of thirteen families were contacted via telephone. They were informed about the research and their eligibility and availability to participate in the research was

discussed. From the initial thirteen families, who were randomly selected, all families met the inclusion criteria and provided consent to be involved in the research. Retention and recruitment was not an issue in this research, possibly as a result of the small scope of the research.

Following the pilot phase, home visits were made to all twelve typical siblings and their parents. All parents provided consent for them to be contacted and involved in the research. Parents were required to be present in the home at the time of the arranged visit. Information about family characteristics and demographics was taken verbally from parents using a prompt sheet and this information was recorded. The purpose of the research was discussed with both parents and typical siblings. Typical siblings were then invited to complete consent forms (Appendix Seven). The developmental stage of all participants was considered in the design of the consent form. Time was also taken to verbally explain the research and the procedure in order to ensure that consent was informed. Participants were invited to ask questions and discuss issues. They were also told that they were welcome to disengage from the research at any stage. Semi-structured interviews were conducted on an individual basis, in a separate room with each participant. No parents asked to be present during the interviews. This would have been discouraged in order to ensure that the information provided by participants was not bias. A series of warm up questions were included at the beginning of the semi-structured interview to build rapport and put the participants at ease. The researcher was conscious of professionalism and time keeping throughout the process. The individual interviews with participants lasted a minimum duration of thirty two minutes

and maximum duration of forty five minutes. This decision was taken to reduce disruptions to the families of the participants. Interviews with all participants were recorded using a Dictaphone. This enabled the interviews to be transcribed at a later stage. Following this phase participants were provided with a written (Appendix Eight) and verbal debrief about the research. Many of the participants expressed concerns during the research and they were subsequently informed about formal support services in the voluntary sector, such as the National Autistic Society (NAS). All participants engaged positively with the researcher and there were no concerns about the concentration and attention of any of the participants who engaged in the research. No participants chose to disengage from the research at any point.

After the semi-structured interviews were conducted they were transcribed. Although this was a time consuming task, this process enabled the researcher to become familiar with the data and this provided a wealth of information. At the point of transcription all personal information was anonymised and each participant was allocated a participant number.

3.6   Ethical issues

Ethical approval for the research was obtained from the School of Psychology in Cardiff University, before commencing the research. Strict ethical guidelines relating to practice and conduct have been produced by the British Psychological Society (BPS) and these guidelines were adhered to throughout the research. In the case of the current research, ethical issues relating to

informed consent, parental consent, storage and protection of data, confidentiality, briefing/debriefing and participant welfare were pertinent as the majority of participants were under eighteen. Lone working issues were also important for the researcher who was conducting home visits. The 'All Wales Child Protection Procedures' were adhered to at all times to safeguard participants.

3.7   Data analysis

Following the completion of semi-structured interviews with the twelve participants, thematic analysis was conducted. Guidance pertaining to nonprobalistic sampling and the concept of saturation, outlined by Guest, Bounce and Johnson (2006) was utilised. This guidance was used and saturation was found to occur after twelve semi-structured interviews with participants. Data from the pilot interview were omitted and not included in the analysis. This process allowed themes to emerge as the data were reviewed.

This method of analysis also acknowledges that the researcher will construct their own meaning from the data and this may influence the process (e.g., constructionist epistemological positions). Thematic analysis also acknowledges that socio-cultural factors impact on the way people attach meaning to experiences through discourse.

Holloway and Todres (2003) emphasised the diversity in qualitative approaches and assert that "thematic analysis should be seen as a foundational method for qualitative analysis" (cited in Braun & Clarke, 2006, p.78). Boyatzis (1998)

defined thematic analysis as "a method for identifying, analysing and reporting patterns (themes) within data". It minimally organises and describes the data set in rich detail. However, "thematic analysis often goes further than this and interprets various aspects of the research topic." (Boyatzis, 1998, cited in Braun & Clarke, 2006, p.79).

Howitt and Cramer (2008) described that thematic analysis is one of the most commonly used forms of qualitative data analysis; however it has received little attention in the literature. The authors suggested that detailed accounts that outline the method for conducting this form of analysis are limited. Other authors (e.g., Boyatzis, 1998; Roulston, 2001) comment that "thematic analysis is a poorly demarcated and rarely acknowledged, yet widely used qualitative analytic method" (cited in Braun & Clarke, 2006, p.77). Aronson (1994) suggested that although there are descriptions of thematic analysis in the literature (e.g., Taylor & Board, 1984; Benner, 1985; Leininger, 1985, cited in Aronson, 1994), there is limited guidance on the process of conducting thematic analysis. This has a number of significant implications for the reliability and validity of this method of analysis across research designs. In an attempt to address these issues, Braun and Clarke (2006) offer guidance for conducting thematic analysis. The authors argue that this guidance "offers an accessible and theoretically flexible approach to analysing qualitative data" (p.77). Issues of reliability and validly are integral in qualitative research as they have implications for the generalisability of findings to the parent population. These issues also have implication for the replication of similar designs in the future. Braun and Clarke (2006) commented that thematic

analysis provides a flexible and accessible form of data analysis that can be used to 'reflect' and 'unpick' reality. Thematic analysis constitutes a less prescriptive approach in comparison to other forms of qualitative analysis (e.g., grounded theory). As a result of the level of flexibility attached to thematic analysis, Braun and Clarke (2006) argued that a number of choices must be considered and made explicit. The authors assert that these decisions should be considered before analysis and that a level of continuous reflexive thinking should take pace throughout the process of data analysis. In response to Braun and Clarke's (2006) guidance, a number of the decisions were considered prior to and throughout data collection.

Decision one: What counts as a theme?

Firstly, a decision had to be taken to define a 'theme'. A rich and varied account of participants' constructions and perceptions emerged from the transcripts and there was a wealth of varied and rich data. Braun and Clarke (2006) assert edthat "a theme captures something important about the data in relation to the research question, and represents some level of pattered response or meaning within the data set" (p.82). The demarcation of codes and themes was based on their prevalence and relevance across the data, in line with Braun and Clarke's (2006) guidance. Themes were identified when there were a number of instances of the theme across the data set. This is left to the professional judgement of the individual/team conducting the analysis. Themes also emerged on the basis of the extent to which they were relevant to the research

question. In the current research initial judgements were made in relation to the prevalence and relevance of themes across the data. A practicing EP with a special interest in ASD, cross checked the data and supported/corrected the judgements.

Decision Two: A rich description of the data set or a detailed account of one particular aspect?

Braun and Clarke (2006) advised that it is important to make decisions with respect to the type of analysis to be conducted. This has subsequent implications for the claims that can be made. Researchers should choose between providing "a rich thematic description of the entire data set" or a "more detailed and nuanced account of one particular theme, or group of themes within the data" (p.83). In the case of a rich thematic description of the entire data set, Braun and Clarke (2006) proposed that depth and complexity can be lost, particularly in a short piece of work. However, the authors comment that a rich comprehensive description remains so the reader gains a sense of the important themes. In the case of the current research the decision was taken to prove a rich thematic description of the entire data set. This decision was made on the basis of the scale of the research and the number of participants, as data are less likely to get lost and 'diluted'. Furthermore, the research is exploratory and aims to capture a range of constructs in order to address the research question, as opposed to providing a detailed and nuanced account of a specific theme or group of themes. The absence of a specific

hypothesis or research question and the exploratory nature of the current research were significant in informing the decision to provide a rich thematic description across the data set. This provided more scope for exploration, particularly as this area of research is still in its infancy.

Decision three: Inductive versus theoretical thematic analysis?

Braun and Clarke (2006), suggested that themes emerge from data in one of two ways. Firstly, themes can be identified in an 'inductive' or 'bottom up' manner, where themes are strongly associated with the data. Themes are not linked to specific questions that are asked and are not driven by a specific theory. This method reflects a data-driven process and data is coded in an open and unbiased way. However, Braun and Clarke (2006) proposed that researchers must still maintain their epistemological commitments.

Secondly, themes can emerge in a 'deductive' or 'top down' manner driven from a specific theoretical basis. This form of analysis provides a less rich description of the entire data set and a more detailed analysis of one aspect of the data with the aim of addressing a specific research question or hypotheses. As the research question was exploratory, an 'inductive' or 'bottom-up' approach was considered most appropriate in order to capture the variety of experiences and relate these to the broad research questions. Also, the disability literature lacks a guiding theoretical basis (Stoneman, 2005). Therefore a deductive approach involving testing pre-determined hypotheses would have been difficult to employ to inform the research.

Decision four: Semantic or latent themes?

Braun and Clarke (2006) encouraged consideration about the level at which themes are identified (e.g., semantic/explicit or latent/interpretive; Boyatzis, 1998). In the case of a semantic approach to thematic analysis, Braun and Clarke (2006) suggested that themes emerge from description to interpretation and the researcher does not attempt to extend this beyond the information that has been voiced by a participant/group of participants. Conversely, thematic analysis at the latent level advances data beyond its semantic content. It attempts to explore the assumptions and constructs that support the ideas emerging from the data in line with a constructionist epistemological basis. This method involves extensive interpretation and theorising and less description. In the current research a semantic approach to thematic analysis was considered most appropriate as it allowed for participants' descriptions to emerge and provided a rich account of their constructions.

Decision five: Essentialist/realist versus constructionist thematic analysis?

Braun and Clarke (2006) proposed that "thematic analysis can be conducted within both realist/essentialist and constructionist paradigms" (p. 85). All research is ultimately concerned with knowledge. Research is considered to be "a process of inquiry and investigation, it is systematic and methodical and it increases knowledge" (Hussey & Hussey, 1997, p.1). Epistemology is extremely important as it is concerned with the nature and construction of knowledge,

which guides the process of research and the subsequent meaning that can be assumed from data. Braun and Clarke (2006) suggested that with an essentialist/realist approach motivations, experiences and meaning is assumed in a linear manner as a result of the unidirectional relationship between language and experience. Conversely, a constructionist approach does not focus on the individual. It endeavours to theorise how socio-cultural factors contribute to individual accounts, which are co-constructed through discourse and language (Burr, 2003).

For the purpose to the current research a constructionist perspective was adopted as it acknowledges that there is no such thing as an objective fact. Participants' constructions will vary and they do not reflect absolute truths. A constructionist approach assumes that knowledge is constructed through discourse and social interaction. Therefore, constructionism will guide the research with the aim of exploring participants' constructions and perceptions in order to generate knowledge. A constructionist perspective acknowledges that language is central to this process and accounts for variability within the group of participants.

In summary, an inductive thematic analysis, exploring semantic themes from a constructionist epistemological position was selected to address the research question. The guidance provided by Braun and Clarke (2006) justifies the choice of methodology. Thematic analysis was employed to generate themes from the data and this process was conducted on the basis of the robust and flexible guidance provided by Braun and Clarke (2006), who have identified six phases that are involved in thematic analysis. A reflexive and reflective approach was

also essential during this process and maintained a level of coherence, consistency and flexibility throughout this 'recursive' process. The following six steps, outlined by Braun and Clarke (2006), were followed during data analysis.

Step one: Familiarisation of the data

Data from twelve semi-structured interviews were transcribed verbatim. The data were read and subsequently re-read and initial ideas were noted. This enabled a level of familiarisation and immersion in the data in an active manner. Bird (2005, cited in Braun and Clarke, 2006) asserted that this phase "should be seen as a key phase of data analysis within interpretative qualitative methodology" (p.227).

Step two: Generating initial codes

Following the initial phase, salient features in the data were coded in a systemic fashion across the whole data set. As previously discussed, a semantic approach to thematic analysis was adopted. Data were linked to specific codes using an alpha-numerical coding method. An example of the alpha-numerical coding procedure used for each transcript is provided (Appendix Nine). Tuckett, (2005, cited in Braun and Clarke, 2006) suggested this process involves organising data into meaningful groups.

Step three: Searching for themes

Codes were subsequently collated into potential overarching themes on the basis of their relevance and prevalence across the data set, as suggested by Braun and Clarke (2006).

Step four: Reviewing themes

At this stage a degree of reflection and reflexivity was required. Following the initial generation of overarching themes, the data were regularly revisited to check the accuracy and extent to which they were representative of the whole data set. Discrepancies, contradictions and inconsistencies in language were considered. Thematic maps were subsequently created for each distinct theme (Appendix Ten). This method of visual representation supported an understanding or the relationship between the themes, subthemes and codes to develop. This also helped to ensure that the map for each theme accurately represented the data set and themes were refined to facilitate this. This process took place over five months, although Braun and Clarke (2006) suggested that this can go on *ad infinitum* and judgements must be made about when to move on to the next phase.

Step five: Defining and naming themes

Once a satisfactory thematic map was in place, themes were refined and clear definitions and names were generated that accurately reflected the story the data told. Each theme was also required to fit with the broad research question

and a degree of reflection and reflexivity was required to ensure this as well as some hierarchical structuring.

Step six: Producing the report

Finally vivid, compelling verbatim extracts from participants were selected to support the themes and provide a story through narrative which addressed the research question. Consideration was given to the fact that the extracts provided concise, coherent, logical, non-repetitive and interesting accounts across the themes (Braun and Clarke, 2006).

3.8   Advantages and disadvantages of thematic analysis

As with many methods of data analysis, thematic analysis has a number of associated advantages and disadvantages. Researchers should be aware of these issues throughout the process of data collection. Consideration should also be given to the potential pitfalls of this method of analysis, such as using data collection questions as themes. Where possible guidelines should be followed explicitly to ensure the analysis accurately reflects the data and addresses the research question.

In terms of its advantages, thematic analysis provides a level of flexibility not found in many other methods of data analysis and it can be tailored to address research questions with a broad theoretical and epistemological basis. This method of analysis is relatively straightforward in comparison to other forms of

qualitative analysis (e.g., narrative analysis, grounded theory, interpretive phenomenological analysis) and can be less time consuming. Braun and Clarke (2006) posited that this method of analysis is therefore attractive to those with limited knowledge and experience of conducting qualitative research. Thematic analysis can also be used to analyse large bodies of raw data and to enable key themes to emerge. The authors also suggest thematic analysis can emphasis similarities and differences and unanticipated findings can emerge from data. The level of flexibility attached to thematic analysis has left it open to criticism. For many years thematic analysis was conducted in the absence of clear and concise guidelines for its use (Boyatzis, 1998; Roulston, 2001; Braun & Clarke, 2006). Thematic analysis was traditionally subjected to the 'anything goes' critique of qualitative research (Antaki, Billig, Edwards, & Potter, 2002) and this method traditionally lacked validity and reliability (Braun & Clarke, 2006). Braun and Clarke (2006) suggest that the disadvantages associated with thematic analysis may have resulted from poorly conducted research designs that fail to provide comprehensive details of the guidelines used. The authors also suggest that the flexibility associated with thematic analysis is significant as researchers can reach broad conclusions about data, which has implications for higher levels of analysis. Braun and Clarke (2006) also suggested that thematic analysis is predominantly descriptive in nature and has limited interpretative power in the absence of a theory to anchor claims.

Chapter Four

Findings

Chapter four provides details of the sample and the demographic characteristics of the participants who contributed to the research (Table Two). The findings from the thematic analysis are also presented, along with verbatim samples from the interviews with the participants, which support the findings. An overview of the themes that address the research question are presented (Appendix Ten). More detailed thematic maps for each theme are also provided (Appendix Eleven). A table is also provided with detailed descriptions of the codes that emerged in as a result of the thematic analysis (Appendix Twelve).

4.1   Sample details

Seventy two gatekeepers across a range of settings were initially contacted. The gatekeepers distributed research packs to families who met the inclusion criteria (*n=48).* A total sample was subsequently identified on the basis of their willingness to participate in the research (*n=36).* From this sample a random sampling method was used to select the sample of participants (*n=13).* One participant was randomly recruited for the pilot phase of the research. However, the data obtained during the pilot phase of the research were not included in the analysis. A broad range of organisations and settings were contacted

and the response rate and break down for each phase of the sampling procedure is outlined (Table Two).

Table Two: Sample information

Setting/ Organisation	Total Number of Gatekeepers Contacted	Total Number of Families Meeting Inclusion Criteria	Total Number of Families Willing to Participate	Total Selected
Local Education Authority	12	18	12	6
Schools	30	15	10	3
Voluntary Organisations	30	15	14	4

There was a fair distribution in the research in terms of the settings/organisations from which participants were recruited. The majority of participants (46%) were recruited through ASD coordinators employed by the Local Education Authority (LEA). A smaller proportion of participants were recruited from schools (23%) and voluntary sector organisations (30%). More detailed information is provided for each participant (Table Three).

Table Three: Participant characteristics

Participant Number	Age of Participant	Gender of Participant	Ethnicity of Participant	Geographical Location	Gender of Sibling with Autism	Age of Sibling with Autism	Birth Order of Typical Sibling	Family Characteristics	Employment Status (of parents)
Pilot	16	Female	Caucasian	South Wales	Male	14	1st	2 parent family (male and female). 2 children.	Employed
1	16	Female	Caucasian	West Midlands	Male	14	1st	2 parent family (male and female). 3 children.	Employed
2	15	Female	Caucasian	South Wales	Male	13	1st	Single parent family (female). 2 children.	Employed
3	17	Male	Caucasian	South Wales	Male	19	2nd	2 parent family (male and female). 3 children.	Employed
4	19	Female	Caucasian	South Wales	Male	18	1st	2 parent family (male and female). 3 children.	Employed
5	15	Female	Caucasian	South Wales	Male	13	1st	2 parent family (male and female). 2 children.	Employed
6	15	Male	Caucasian	South Wales	Male	17	2nd	2 parent family (male and female). 2 children.	Employed

Participant Number	Age of Participant	Gender of Participant	Ethnicity of Participant	Geographical Location	Gender of Sibling with Autism	Age of Sibling with Autism	Birth Order of Typical Sibling	Family Characteristics	Employment Status (of parents)
7	16	Male	Caucasian	South Wales	Male	13	1st	2 parent family (male and female). 2 children.	Unemployed
8	17	Male	Afro-Caribbean	South Wales	Male	14	2nd	2 parent family (male and female). 2 children.	Unemployed
9	19	Female	Caucasian	West Midlands	Male	17	1st	Single parent family (female). 2 children.	Unemployed
10	17	Male	Caucasian	West Midlands	Male	13	1st	2 parent family (male and female). 2 children.	Unemployed
11	16	Female	Caucasian	West Midlands	Male	13	1st	2 parent family (male and female). 2 children.	Employed
12	13	Female	Asian	West Midlands	Male	16	2nd	2 parent family (male and female). 2 children.	Employed

Originally, participants aged between eight years and twenty years were invited to engage in the research. However, it is clear from Table Three that a narrower age range of participants were ultimately selected to participate in the research. Typical siblings aged between thirteen and nineteen years engaged in the research (*mean age = 16.25)*. The brothers of the typical siblings who had a diagnosis of autism were aged between thirteen and nineteen years (*mean age = 15)*. This creates a bias in the sample, despite the fact that a random sampling procedure was used. However, this may provide more specific information about an adolescent sample which can be related to the research question.

In terms of the diversity and representativeness of the sample, the majority of the participants were Caucasian, however other ethnic groups also participated in the research (e.g., Asian, Afro-Caribbean). The participants were also from two geographical locations. The majority of typical siblings were older than their brother with autism (66%). For the older typical sibling participants the average number of years (e.g. age spacing) between typical siblings and their brothers was considered (*mean age spacing = 2.3 years).* However, a proportion of typical siblings were younger than their brother with autism (33%). For the younger typical sibling participants the average number of years between typical siblings and their brothers was considered (*mean age spacing = 2.5 years).* Although attempts were made to recruit participants from a range of different families, there was a bias in sample. The majority of participants came from two-parent families

(83%). A smaller number of participants came from single-parent families (16%). Restrictions were also made during the recruitment phase of the research and families with more than three children were excluded from participating to control for the effects of family size. However, there was a bias in the research and the majority of participants lived in families with their brother with autism (75%). However, a smaller proportion lived with their brother with autism and another typical sibling (25%). The majority of typical siblings came from families where parents were employed (66%), whilst a smaller proportion came from families where parents were unemployed (33%).

4.2   Identified themes

A variety of themes emerged from the data on the basis of their prevalence and relevance. The data were analysed using thematic analysis and nine overarching themes emerged to inform the research question (Appendix Ten). A description of each theme is provided and detailed thematic maps are also included (Appendix Eleven). A definition of each theme is provided and verbatim extracts from the transcripts are provided to support each theme. A more detailed outline of the codes that contributed to the development of each distinct theme is provided (Appendix Twelve).

4.2.1 Theme one: Knowledge and understanding of autism

All participants were asked what they knew about autism. Participants varied in the extent to which they were able to demonstrate knowledge and an understanding of their brother's condition. Two participants displayed limited knowledge and understanding of autism.

> Participant one: *"Very minimal really. I only know what I have seen from my brother". (p.1)*

Some participants (n=3) described their brother's condition in terms of a psychological or mental impairment.

> Participant eight: *"All I know is that it affects the way that my brother (=insert name of sibling with autism=) is able to see things. He sees things in a different light". (p.2)*

> Participant ten: *"It's something that is like a birth defect and something that is to do with the mind. It's like they are missing a piece or a part of their brain is damaged. They can't think straight or have the ability to reason". (p.2)*

> Participant eleven: *"I would describe it as like a mental condition". (p.1)*

The majority of participants (n=8) described their brother's condition in terms of psychological impairments and behavioural difficulties. These participants attributed these difficulties and impairments to their brother's condition.

Participant two: *"It's a part of some kid's brains when they can't interact with other people. There are like all different types of them. I have got an autistic boy in my class and he is like really smart and he can interact but he just goes crazy over some things". (p.1)*

Participant three: *"I know there are lots of forms of autism (long pause) lots of other forms of it. I mainly know about autism because that is what my brother has. There is Aspergers too isn't there (pause), which is a bit similar. I know it's where like he finds it harder to understand things and like it takes him more time to understand things and he's not as good like socially I find as well. He hates big changes and crowded places". (p.1)*

Participant four: *"It's a social interaction disability and communication difficulty". (p.1)*

Participant five: *"It's like when you don't have the right communication skills and you find it hard to control your emotions".* (p.1)

Participant seven: *"Sometimes like he stays up really late. If he is around loads of people he can be demanding. Like and (pause) if it isn't by his own words and he gets told something by someone else and then another person then he will believe the person who told him first".* (p.2)

Participant nine: *"I always say it's like he's sort of in his own little world. That's what I say, it's just always easier. I will say like he won't look you in the eye and things like that".* (p.1)

Participant twelve: *"It's like some type of brain damage and their brains are not the same. This means they don't like see the world like we do. They also have no imagination and stuff (pause) and argue with friends".* (p.2)

One participant described their brother's condition in terms of behavioural characteristics or difficulties that they attributed to their brother's condition. This participant may have been constructing their brothers' condition on the basis of based on their phenomenological

experiences in the absence of having a more comprehensive understanding of autism.

> Participant six: *"Well it's like the way he acts really. He takes things really seriously and constantly asks questions. Like if my mum says be in at eleven he asks why over and over and over again. He likes reacts badly to things sometimes too".* (p.2)

4.2.2 Theme two: Perceptions

Participants were asked to describe their brother with autism. A proportion of participants communicated that they perceived their brother in a positive manner (n=6), albeit to varying degrees. Participants demonstrated positive perceptions, irrespective of the frequency and severity of aggressive/disruptive behaviours and negative experiences. However, participants who frequently engaged in shared activities and experiences and who were not the target of aggressive/disruptive behaviours had more positive perceptions of their brother. Furthermore, participants who had fewer concerns about differential attention and treatment from parents also had more positive perceptions of their brother.

> Participant two: *"To some people he doesn't really want to talk and he keeps his distance, but like with me he always comes up*

to me and he likes to play and give me hugs and stuff. I have heard about some people who don't really like their brothers with autism, but it makes me feel good when we hug (pause) I feel really glad that I have got a brother like that".(p.2)

Participant three: *"Lively and fun". (p.2)*

Participant six: *"He can sometimes be helpful and that". (p.2)*

Participant seven: *"Funny. Like really active. Really good on computers and stuff like that. He likes to ride bikes and stuff". (p.2)*

Participant eight: *"Sporty (pause). He likes doing things. He is quite active I guess. He can be quite practical too". (p.2)*

Participant nine: *"Erm (long pause) he is quite quiet and he just sits on the computer. He is funny and he comes out with (pause) something (pause) and then he will come out with something normal like "oh my gosh". It's so funny because he never says things like that. Erm I don't know what other words (pause), he is happy a lot of the time". (p.1)*

Participant ten: *"Ever since I was young (long pause), I always felt that the attention was from me to him. It's natural. When I was younger I hated it".* (p.3)

Some participants (n=6) communicated that they perceived their brother more negatively.

Participant four: *"Moody. Oh yes and very withdrawn. He sort of stays in the background".* (p.2)

Participant five: *"He's really temperamental and young for his age".* (p.2)

Participant eleven: *"My brother is quite aggressive and he won't shut up when he is talking."* (p.2)

Participant twelve: *"He can be moody (pause). He sometimes has bad tantrums. He spends a lot of time on his own. We don't like do lots together".* (p2)

4.3.3 Theme three: The quality of the inter-sibling relationship

Participants made sense of the quality of the inter-sibling relationship in different ways. Some participants (n=6) viewed their relationship with

their brother in a positive manner. Constructs such as warmth and closeness tended to guide these participant's constructions of the quality of the inter-sibling relationship. Engagement in joint activities and shared experiences also appeared to feature on a consistent basis when participant described positive inter-sibling relationships.

> Participant two: *"My relationship with (=name of sibling with autism=) is like completely different to normal brothers and sisters. He sometimes just cries and he will like come to me and my mother for like comfort, but at the same time we both like going on the trampoline and he never used to like letting me out. We both just like watching TV and going on the Wii and stuff".* (p.2)

> Participant three: *"We are quite close and we spend a bit of time together. We are in the same swimming club. We go out in the car sometimes and go driving, you know stuff like that".* (p.2)

> Participant four: *"Yes we are quite close. We went on holiday in February with my friends. Yes we go shopping and stuff. I am happy to spend time with him with just us two. He tends to chat more then".* (p.2)

> Participant seven: *"It's good that we can play together".* (p.4)

Participant nine: *"We play games and make cakes and stuff. I am quite strict with him. I will like make him do stuff for himself. We are kind of like a normal brother and sister and we are really close"*. (p.2)

A number of participants (n=7) described their relationship in a more negative manner. These participants tended to view their relationship with their brother as being distant and lacking in dimensions such as warmth and closeness. Participants who had more negative constructions of the quality of the inter-sibling relationship often described how they did not share common interests or engage in joint activities with their brother. Some participants described that their brother's impaired social communication made it challenging to form a close inter-sibling bond.

Participant One: *"We are very distant. The only thing we have in common is our music. We listen to the same music and that's about it. We are very, very distant from each other. I don't really know him that well to be honest, because he is so withdrawn. You just can't get into his world. He's so in himself"*. (p.2)

Participant five: *"We have nothing in common, and we don't really do anything together; he doesn't like doing anything I like*

doing. We really are not that close. (Pause) he doesn't want to do much with me really". (p.2)

Participant ten: *"He doesn't always understand me and he just believes what goes on in his mind. He just thinks that is right". (p. 2)*

Interviewer: *How do you get on with one another?*

Participant eleven: *"It varies really, but normally it is not very good". (p.2)*

Interviewer: *"Are you close?"*

Participant eleven: *"No, not really I guess we are very distant" (p.2).*

4.2.4   Theme four: The impact of their brother's condition

Growing up with a young person in the family with autism can, in some cases, be extremely challenging for all family members. All participants described that having a brother with autism impacted on their life in some way. However, participants' views varied greatly, which may be due to the variability in both the presentation and severity of autism

between individuals. All participants (n=12) commented that their brothers had a negative impact on their lives, albeit to varying degrees. A number of participants described how differential treatment and attention from parents (n=6) had a negative impact on them, particularly during middle to late childhood.

> Participant one: *"Well there was a period when there was a big problem with (=name of sibling with autism=) because I always felt that he was molly coddled and he was the favourite child. I felt like I was being pushed out really. It didn't like take over my life but it was really bad and affected me the most when I was about ten or eleven. When I was little I always felt that (=name of sibling with autism=) was the favourite and stuff". (p.3)*

> Participant two: *"Well, mum gives me more gifts because he has had a lot of things in the past and I was always left out. She treats me and takes me out now to make up for all of that". (p.4)*

> Participant four: *"Our family does revolve around (=name of sibling with autism=). I think because he always needed so much attention when we were younger and support, that I took more of a back seat. So I guess (pause) when I was younger my parents would have had a lot more time for me. It was hard because I was an only child, then my parents had (=name of sibling with*

autism=) and when he was a toddler I had to fit in with (=name of sibling with autism=) to get my bit of time from mum and dad". (p.3)

Participant six: *"He gets his own way a lot". (p.3)*

Participant eleven: *"I generally get away with a lot less which isn't fair. Like with mum and dad. I know they definitely try but I just don't get as much time". (p. 3)*

Participant twelve: *"Like I had a new I pod touch and he threw that in the kitchen and it broke. I was really upset about that and he like just gets away with a lot more than me. I can't do anything back because I know it's the autism that is making him this way, but I sometimes feel like it's unfair and in the past I went and broke some of his stuff and then I got a huge row". (p.2)*

One participant described that she actively attempted to excel in academic work and extra-curricular activities to gain parental attention.

Participant twelve: *"I don't get much time from mum and dad because they are so busy with (=insert name of sibling with autism=). I think that by doing well in all my activities, music and*

at school and by being happy and stuff that they might notice me more. It's just mum and dad really notice when I do well in those things. That makes me feel better and good in a way, like at least I am doing something right". (p.3)

Some participants (n=4) described that they were required to support their brother and had responsibilities for caring and assisting them on a daily basis. The degree to which participants viewed this as a burden varied between individuals.

Participant three: *"Well just one thing really. It's the understanding. I mean sometimes I have to like say things, then you have to like say it again, and maybe even a third time until like he can get it. Sometimes he kind of like, if he tries to describe something (pause), he will just like give up half way through. He doesn't think he can get it across. So it's silly little things really. I try to help when he is trying to get something across I try to encourage him to try anyway. So, like at least he is giving it a go. When he really doesn't understand I just try to like break it down into really simple steps for him". (p.2)*

Participant four: "*Well (pause), I worry about him. He has just started going out like any normal teenager and I sometimes go with him, or offer to pick him. I make sure I am sometimes in the*

same places as him so that I can keep an eye on him. I worry about him getting into trouble I guess as people don't understand him sometimes". (p.2)

Participant four: *"You know sometimes if he is left to get on with things too much it will lead to a much bigger issue later. So you have to be constantly on top of him and in control so you don't have problems later".* (p.3)

Participant nine: *"Yes, I would and at night he can get really upset, and he cries and like I would lie in bed with him and make sure he went back to sleep. He would keep waking up, and sometimes I would be up all night with him. It's normally when a big change happens that always seems to upset him".* (p.3)

Participant twelve: *"I also try to help in the house because mum and dad have a lot to do and I help (=insert name of sibling with autism=) with some of his work sometimes. I help a lot and do a lot actually (pause), I don't have as much time for me because of (=insert name of sibling with autism=)".* (p.3)

Interviewer: *What sorts of ways do you help (=insert name of sibling with autism=)?*

Participant twelve: *"Like writing and letters and things like that. Day to day stuff too (pause) like cleaning, cooking, washing. Lots of things. I don't do the things I want to do, because there are so many other things I have to help with".* (p.3)

A number of participants (n=9_) described how their brother's behaviour had a negative impact on their daily lives. This included disruption to sleep, education, concerns about transitions to higher education and difficulties forming and maintaining relationships with peers.

Participant two: *"Sometimes he like is just upstairs and say I am like here doing my homework and I have to concentrate; all of a sudden he might just start screaming. Then like if I am sleeping he might just come in during the night and turn all the lights on. That wakes me and makes me really tired and annoyed".* (p.3)

Participant four: *"My school work really suffered then. I also just started university this year and I was worried about going, although I looked forward to going too. It was more worrying about mum".* (p.4)

Participant six: *"Like say now if he's like in, or if I am out (pause), he will like come into my room and trash it and make a mess. He*

comes in and hogs the computer too because he really loves computers. He won't share it and he stays on it for hours and hours which can be really annoying if I need to use it or if it's getting late and stuff. He breaks my stuff. I sometimes ask him to get out and he won't leave and then he kicks of". (p.3)

Participant six: *"Well sometimes I couldn't sleep because of him and I would get really angry".* (p.3)

Participant seven: *"If I have friends over who don't know then I do worry a bit. I tell them not to worry though and just say "he won't touch you or anything, so don't worry". So I would tell them and hope they don't panic about him. He can be a bit odd in front of new people, when they come home with me".* (p.4)

Participant eight: *"Well because of the fact that his autism is quite bad. You have to tip-toe around him, especially in the morning because that is when he is at his worst. Especially during school time".* (p.2)

Participant eight: *"Like in school (pause), he doesn't have many people to hang around with and he finds it hard to make friends, so he would hang around me which wasn't much of a help. I had my group of friends and he would hang around and be a bit over*

the top sometimes so they sort of distanced themselves from me. So I was just stuck with him literally clinging on so that was a bit of a pain. (Long pause) I haven't ever brought a friend home. I don't really keep friends because of my brother". (p.4)

Participant eight: *"When he kicks off in the mornings I go to school and I am really worried because I don't know what he is going to be like. I can't concentrate then. That's the hard thing (pause) I just worry". (p.4)*

Participant nine: *"I would be like watching programmes on TV, and he would just scream, and I didn't know why and then I would get a row because mum would think I was pestering him and stuff. The Sound of Music was my favourite programme when I was little and as soon as it came on he would just cry and scream". (p.2)*

Participant nine: *"I remember night times always being the worst. Like (pause) if he didn't want to go to bed he would scream at the top of his lungs, and I was always going to bed at two or three. I would miss school the next morning because of that. I know he used to scream a lot. Like at the supermarket if any noise came over the speakers he would literally scream and scream". (p.2).*

Interviewer: *"Does having a brother with autism affect your life?"*

Participant nine: *"The lack of sleep and not getting up. It wasn't all the time but when it happened I did miss a fair bit of school and things like that. With friends, like I think once. I brought a girl who was a bit snooty here and I was like oh my god how am I going to explain (=name of sibling with autism=) to her". (p.2)*

Participant ten: *"Sometimes he sort of easily gets into a bad mood, and sometimes he gets into a mood when he just gets angry at anything and you have to be really careful around him then. He's very temperamental when it comes to moods. I mean if you move something and he sees you, then he will get really angry and sometimes he will just storm off even if you mention his name". (p.2)*

Participant eleven: *"Well, normally I get woken up to the sound of guitars which is really irritating, when it is early in the morning". (p.2)*

Participant eleven: *Well, I am constantly on edge, and I just have to stay out of his way. It did affect my GCSE's a little bit because obviously it's hard to revise when you have slamming doors and*

music. Like the temper tantrums and noise when I was revising for my GCSE's was really difficult too. Like with maths I hate it and then I just can't concentrate and I find that really difficult and can't stop thinking about what happened at home". *(p.2)*

Participant eleven: *"I brought one new friend home recently and she was a bit intimidated but she was fine after a while. I think I would have to plan it if I bring new friends home (pause) like think about the sort of day he is having. I couldn't just bring someone new back that would really worry me". (p.4)*

Participant twelve: *"Before my exams he started to get really funny about the light and stuff and he would like barge into my room when I was revising and turn all the lights out. It was hard in the winter when I was studying, because I would have to have a torch in bed not to let him see and if he came in I had to turn it off quickly and pretend to be sleeping. He wouldn't knock or anything. I think that affected my results quite a bit really". (p.3)*

Participant twelve: *"I don't like having my friends over much, because I worry in case one of them says something that he doesn't like and if he hurts them that would be so bad". (p.4)*

Some participants (n=5) also described how they were the target of aggressive and violent behaviour, which they described as having a negative impact on them.

Participant six: *"Well it can be really bad sometimes (pause). He will like start on my mother. If he goes too far I will like step in. He usually shouts abuse at her and sometimes he will like go for her and stuff. I usually like step in and try to hold him back".* (p.2)

Participant eight: *"It can be hard, because normally I am the first one that he attacks".* (p. 3)

Participant ten: *"Well sometimes he is sort of violent and he just lashes out every so often. Like you know if he gets into a fight or whatever he punches me, and I just have to sit back and cope with it. I mean I can't punch him back. He shouts and screams and storms off too. He swears at me and has tantrums and he can like rampage and breaks stuff".* (p.3)

Participant eleven: *"He can be really aggressive towards me. He can be really angry towards me and like slams doors and yeh. He like slammed the front door the other day and the whole house shook. I don't know why he does it, it could be anything. It is*

usually something I have done. If he doesn't like something I do

or agree with something I say". (p.2)

Participant twelve: **"***The other bad thing is like his temper and*

stuff. He can get really angry and I don't always know why. He

takes it out on me and mum and sometimes I have had like

marks and bruises when he has hit or kicked me and that makes

me sad and that's really hard. He can throw stuff and he has

broken things". (p.2)

A minority of these participants (n=2) described that they were required

to mediate conflict between parents and their brother with autism.

Participant six: "*I would stick up for mum, even though I am*

youngest. I just wanted to help mum, it's not fair on her". (p.4)

One participant spoke about how she becomes triangulated in inter-

parental conflict as a result of her brother. The participant described

the impact on her relationship with her mother in particular.

Participant eleven: "*With mum and dad. I know they don't mean*

it but if he goes off on one they usually take their anger out on

me because they can't take it out on him. I just get caught in the

middle. It might have affected my relationship with mum because she takes her anger out on me". (p.4)

Some participants (n=5) also described how their brother's difficulties had a negative emotional impact on them.

Participant three: *"Sometimes I feel really frustrated". (p.3)*

Participant four: *"There was a time when I felt really low". (p.4)*

Participant five: *"I get a bit frustrated and feel a bit gutted and let down sometimes" (p.2)*

Participant eight: *"I feel a mix of things and lots of emotions (pause) like anger (long pause) totally upset and totally in like a whirlwind of emotions. Normally I end up showing tears really more than anything". (p.5)*

Participant eleven: *"I get more withdrawn and I am a lot more defensive. Like (pause) really irritated. I feel more depressed too. I think it's all because of (=insert name of sibling with autism=)". (p.3)*

Participant twelve: *"It can make me really sad. I cry sometimes".*

(p.4)

Two participants described that having a brother with autism restricted the amount of activities and time they could spend together as a family. These participants described how limitations and restrictions had been placed on frequency and range of activities they could do as a family during leisure time.

Participant five: *"Going places can be really difficult. He hates loud places and he can't sit anywhere for long. We can't just think oh I fancy going to the beach or pool or whatever. We always have to think. If we go somewhere he can be really difficult and moan and lash out. We don't do as many things that I would want to do because of him". (p.2)*

Participant eight: *"We have to always do things that (=name of sibling with autism=) wants to do, and we all have to keep him happy". (p.4)*

However, a number of participants (n=8) described that having a brother with autism had a positive impact on their lives. A minority of participants (n=3) described that their brother frequently supported or helped them.

Participant six: *"I don't know if it's to do with his autism but he sometimes like takes an interest in one subject. His interest is like computers and if one of us needs help he can sometimes be really good at sorting this out. I had maths homework and he is really good with maths so I asked him if he could help me and he helped me and like I got them all right and that"*. (p.2)

Participant seven: *"Sometimes he teaches me loads of stuff on the computer and he helps me out with my bike"*. (p.2)

Participant nine: *"He is good with computers. He can always fix my computer for me"*. (p.2)

A minority of participants (n=2) also enjoyed supporting and helping their brother.

Participant two: *"It's good because I get to help out. I help with his reading and his numbers and all of that. Like we used to have a little school up in the attic in my old house and we used to teach him lots of stuff"*. (p.2)

Participant five: *"I read to him and that's really good because I know that's something we both want to do and enjoy doing"*. (p.2)

Some participants (n=5) described that having a brother with autism had a positive impact on their personal development and development of self concept. These participants described that they were empathetic and less judgemental of others, as a result of having a brother with autism.

Participant three: *"If you see somebody else with a problem, I think I am a bit more understanding and can empathise more with people's problems". (p.3)*

Participant five: *"I would never judge people now with special needs". (p.3)*

Participant seven: *"I think because my brother with autism is really strong that I have grown up fighting with him that has helped me to learn to stick up for myself". (p.2)*

Participant nine: *"I now think I have a lot more patience in every aspect of everything I do because I have learnt to be patient with (=name of sibling with autism=)". (p.3)*

Participant ten: *"I mean it's given me more patience and a greater depth of understanding and willing to understand other*

things. You know you can't be prejudice about one person and

it's not their fault". (p.3)

Two participants reported they were interested in working in a helping profession, as a result of their experiences.

Participant four: *"Yes I appreciate how difficult things can be for families. I want to be a teacher to help families and children with special needs". (p.4)*

Participant five: *"I am hoping to be a speech therapist or psychologist in the future I really want to help people now. I want to do something like that because of helping my brother at home. I find it really interesting". (p.3)*

A minority of participants (n=3) described that the difficulties they experienced as a result of having a brother with autism, had a positive impact on their relationships with their parents and that their family was stronger as a result.

Participant four: *"We are closer now and I think this could be because of (=name of sibling with autism=)'s autism". (p.4)*

Participant nine: *"With me and mum, I think we are closer because of it"*. (p.2)

Participant ten: *"I think it has made my family stronger in a way, because we all like have had to learn how to cope and stuff"*. (p.4)

Some participants (n=2) described that their brother's condition had a positive impact on their lives and commented that there was less conflict and rivalry between them, because of their brother's condition.

Participant five: *"Like other brothers and sisters argue a lot. I don't really argue with (=name of sibling with autism=)"*. (p.2)

Participant twelve: *"We don't argue or like try to be better than each other like other families. Like some of my friends. They have to compete for better grades and results with their brothers and sisters and we don't have that. I guess it's a lot less stressful in that way"*. (p.2)

Half of the participants (n=7) described they felt a sense of loss or grief as a result of not having a typically developing sibling. These feelings were associated with the fact that typical siblings were acknowledging the reality of their situation and their brother's difficulties. Many of these participants contrasted their own inter-sibling relationship with

the inter-sibling relationships of typically developing individuals in their peer group.

Participant one: *"(=name of sibling with autism=) would have a more normal life too. He would have friends and stuff. At the moment he doesn't really have friends". (p.3)*

Participant nine: *"Like I still have to baby sit him and he is seventeen". (p.2)*

Participant ten: *"I always wondered what it would be like to have a normal brother like all my friends and that". (p.2)*

4.2.5 Theme five: Coping strategies

All participants identified specific stressors that affected them to different degrees. Differential treatment and attention, embarrassment and stigma and physically/verbally aggressive behaviours directed at the typical sibling were appraised as stressful for participants. Additional stressors included interparental conflict, the requirement to mediate family conflict, difficulties with peers and worries or concerns about their brother with autism. Participants coping responses varied in response to specific stressors. They did not appear to differ as a function of participant age or gender.

Some participants (n=3) adopted problem focused strategies following difficulties. In these cases participants attempted to adapt their own behaviour in an attempt to cope to reduce stress. A minority of participants (n=2) attempted to increase their knowledge and understanding of autism or learn new skills (e.g., behaviour management techniques). These strategies reflected practical and active attempts by participants to improve their situation.

Participant eight: *"I just usually stick my headphones on and if he has a tantrum I just don't hear it". (p.4)*

Participant nine: *"Like we used to do the counting down thing". (p.3)*

Participant ten: *"There are many techniques. You can either try and you know calm him down and move on to another activity or something. When he is angry you can like mention something good and he instantly just changes and he can be happy again". (p.4)*

Some participants (n=4) adopted appraisal focused strategies and appeared to attempt to adapt their perceptions and cognitions in an attempt to cope.

Participant one: *"It's understanding that they cannot help the way they are"* (p. 2).

The majority of participants (n=9) adopted emotion focused strategies to cope in response to stressors, These strategies included disclaiming, escape-avoidance, accepting responsibility or blame, exercising self-control, seeking social support and positive reappraisal.

Participant one: *"Well I spoke to my parents about it a lot". (p.3)*

Participant three: *"I'd talk to my family. Mum and dad mainly". (p.3)*

Participant four: *"I just became really really quiet and used to take myself off to my room a lot... I became quite low and withdrawn for about three years or so". (p.4)*

Participant seven: *"With most stuff I just keep it to myself". (p.5)*

Participant eleven: *"I just spend a lot of time alone in my room". (p.2)*

Participant twelve: "*I try to stay out of the way and not get involved. If he goes for me I try to run away or just curl up in a ball with a pillow or something, so he doesn't hurt me*". (p.4)

These coping mechanisms did not appear to be consistently linked to a specific stressor or trigger and all the participants used these coping strategies interchangeably. However, the more significant stressors (e.g., physically/verbally aggressive behaviours directed at the typical sibling and differential treatment and attention) frequently resulted in emotion focused coping. One participant described that she felt more able to cope with difficulties and stress because she spent more time away from the home. This may reflect the increased emphasis on peer relationships and increased attempts to achieve independence during adolescence.

Participant one: "*It just doesn't bother me now. I have my own life and I am busy. I just get on with things. I'm not home as much, and I tend to spend a lot of time with my friends and round their houses and stuff*". (p.3)

4.2.6 Theme six: Perceptions of others

The majority of participants (n=11) described how they had negative experiences when they were out in public with their brother. They

reported they had to deal with discrimination, misunderstanding and prejudice. Some participants described feeling anger or embarrassment as a result of social stigma.

Participant seven: *"He has a lot of problems like (pause) he upsets people. He says stupid things sometimes and I just want to die. He's quite embarrassing".* (p. 4)

Participant ten: *"It's annoying when people don't understand autism as well and they don't understand him and they make fun of him on the street or whatever".* (p.2)

Participant ten: *"They think that he is like mentally disabled and whatever and that he can't do things and shouldn't do certain activities. Some people think he is like a different species".* (p.3)

Participant twelve: *"People stare at him and say silly things. People call him mental or a freak and that really upsets me. I wish people wouldn't look as much and stuff because it makes him worse and then I get really embarrassed (long pause) especially if we are in town shopping, or something because people from school might see and stuff".* (p.4)

Two participants described that they experienced difficulty explaining autism to the public and spoke about how people were often curious about their brother's condition. These participants also reported that they found it challenging to explain autism to others.

> Participant three: *"People are generally quite surprised and shocked really. I have to sort of then explain about his difficulties with understanding and that. Lots of people just don't get it". (p.3)*

> Participant five: *"Most people don't really understand autism because it doesn't really affect them. They might just think he is really odd or something. Well some people can be a bit sort of wary of him". (p.4)*

Some participants (n=4) described that other children and young people's attitudes towards their brothers were negative. These participants described they experienced difficulties with peers as a result of negative reactions towards their brothers. Three participants explained that they had been required to adopt defensive roles to protect their brother and that they had been forced to mediate conflict in their peer group.

Participant two: *"I can remember he was in the corner spinning and people would come up to him and they would shove him and stuff. So I went up and helped him and told them to all stop what they were doing. I just went mental on them. If anyone bullies anyone with autism I will stand up and say there is no point because people with autism cannot help how they are and things".* (p.3)

Participant six: *"I stand up for him a lot and try to look after him".*
(p. 3)

Participant ten: *"You have to like defend him".* (p.2)

Four participants indicated that they found it particularly difficult to explain the construct of autism to the public. They reasoned that this was because autism does not have any obvious physical disabilities that are associated with the impairments observed in those with autism.

Participant one: *"The thing is people don't see any physical differences really and (=sibling with autism=) just looks like a normal boy. Then, he has all these rituals, like he laughs to himself and pulls faces. This is a bit out of most people's comfort zone when we go out and stuff. People look and laugh".* (p.3)

Participant three: *"With my brother I think if I tell them, half of them are surprised. It's not obvious that he is disabled".* (p.3)

Participant four: *"Lots of people can't see why he has special needs".* (p.3)

Participant eleven: *"Normally it's difficult because people cannot see he has a disability".* (p.3)

4.2.7 Theme seven: Support

All participants (n=12) described that they accessed different forms of support at some point in time. The majority of participants made use of informal support services (n=2). A minority of participants (n=2) reported that they accessed formal support services in the past.

Participant two: *"I saw a counsellor in school for a while and that was good".* (p.5)

Participant nine: *"I went to PALS like I enjoyed that. It's like a group. It really helped me to understand him so I found that helpful but that was only a one off thing so more of that would have been good".* (p.4)

As previously mentioned a large proportion of participants (n=10) made used of informal support, such as talking with family members who would understand their situation, or confiding in friends.

Participant one: *"Well if I ever have any problems, my mum or dad". (p.4)*

Interviewer: *"Are you able to get help and support?"*

Participant three: *"Yeh, from mum and dad". (p.4)*

Participant three: *"I sometimes talk to my best friend". (p.5)*

Participant nine: *"I would go to mum too. I could always talk to her". (p.4)*

Participant eleven: *"Yes I can talk to my friends. Sometimes I talk to mum and dad, but mainly mum". (p.3)*

A minority of participants (n=2) spoke about barriers that prevented them from accessing informal support. One participant described that she felt unable to share her concerns with her parents, as she did not want to burden her parents with additional stress.

Participant twelve*: "I talk to mum if I am sad, but she gets quite upset and I don't always like telling her things. Everyone has problems and they don't need to listen to mine. Especially mum and dad (long pause) with everything they had to cope with". (p.5)*

One participant described that he did not feel he ever needed to access any form of support, as he wanted to be independent.

Participant ten: *"I never felt like that I have needed to, because I always wanted to be independent". (p.4)*

The vast majority of participants (n=10) identified a lack of provision and support and described the types of services they felt could help them and other typical siblings of young people with autism.

Participant four: *"I wish there had have been something and that there was something now. People just don't understand how hard it can be for brothers and sisters". (p. 4)*

Participant eleven: *"For siblings in general I think there could be a lot more". (p.5)*

A number of participants (n=5) felt that sharing their concerns and engaging in dialogue with other typical siblings of children and young people with autism could be beneficial.

Participant one: *"I suppose like a group could help so like people can come together and like arrange stuff about autism. If you got into a room and talked you might find it good to share things and find that you have things in common". (p. 4)*

Participant three: *"Maybe a support group like the one my parents go to. I think if you understand and know more about autism then that might be more helpful". (p. 4)*

Interviewer: *"In what ways could be more support or help for you or other siblings of children with autism?"*

Participant four: *"I guess at the difficult points it would have been good to go to a group like my parents go to. Maybe I would have made friends with other siblings then we could have talked and this would have also given my mum some time out. She might have been less stressed then and that would have been better for all of us". (p.4)*

A minority of participants (n=3) felt that support to develop their knowledge and understanding of autism could be helpful.

> Participant ten: *"It would have been helpful (pause) maybe to talk to someone and maybe it still would be. Like people who have an autistic brother and who understand and could give advice...I am always open to learn more about autism (long pause) there is so much more to learn". (p.4)*

Other participants (n=2) reported that access to counselling or therapeutic services could support them to cope with the difficulties associated with having a brother with autism.

> Participant twelve: *"Just (pause) someone to talk to (pause), who understands what it's like, but not someone in the family. Maybe (pause) someone who you could be really honest with and who wouldn't judge you and someone to help you". (p.5)*

4.2.8   Theme eight: The future

A number of participants (n=10) voiced concerns about the future. A number of participants (n=5) described that they were growing increasingly concerned about the future as they progressed throughout adolescence and developed an awareness of mortality. Participants who

were older in developmental status, in two sibling families and who were older than their brother with autism were observed to voice the most significant concerns about the future.

Some participants (n=6) were particularly concerned about the burden of caretaking responsibilities for their brother in the future.

Participant one: *"Well it's becoming a concern about when my parents, you know, (pause) pass away. They are going to have to put something in place for (=name of sibling with autism=), and then it's going to be like kind of my responsibility. I'm not saying I'm going to take (=name of sibling with autism=) and he will be my son, but I'm going to have to be the one who looks after him"*. (p.4)

Interviewer: *"How do you feel about the future?"*

Participant one: *"I'm scared. It's really scary because I know my parents will put the best possible system in place. But, then what if that goes wrong? I mean how will I deal with it and what will I do?"*. (p.4)

Participant two:*" It makes me feel a bit sad because I know I can't just pop over to see him. I will have to make sure he has someone to look after him all of the time"*. (p.4)

Participant five: *"I don't think he will ever live on his own, and he is always going to need my help. It really worries me"*. *(p.4)*

Participant ten: *"With my brother he is autistic so I have to think right he can't do much for his future so you know I start to think how I can help and stuff like that. It's a big worry for me to be honest"*. *(p.5)*

Participant twelve: *"I think I might have to help and look after him... I am worried about this, like if he can't go to school when he is too old he won't be able to get a job... I think this could be quite hard and I am a bit worried about this"*. *(p.5)*

One participant described concerns relating to behaviour management in the future.

Participant eight: *"I'd be quite worried because by that point he is going to be quite big and quite strong. I mean he is strong now you know. As it is I can just about contain him and even dad has trouble... If he gets any worse or any stronger he is going to be really difficult to handle"*. *(p.5)*

A number of participants (n=4) were concerned about the impact their brothers would have on them and their independence in the future.

139

Participant one: *"I worry more now that I am getting a bit older and thinking about my own future. I worry that I won't have any help with (=name of sibling with autism=) when I have my own job and family. I worry that I won't know how to deal with things if it all goes wrong".* (p.4)

Participant four: *"I will always have to be there for him no matter what is going on in my own life... I would rather he have me than no one, you know".* (p.4)

Participant eight: *"It might affect my future... I may have to take him in one day".* (p.5)

Participant eleven: *"I am worried because I am always going to be a bit tied down and have to live close to him and stuff. It's really difficult and definitely worries me".* (p.5)

Two participants expressed no concerns about the future. One participant came from a larger family and had an older sister who had adopted more caretaking responsibilities for her brother. This may have reduced the burden of caretaking responsibilities in the future for this particular participant.

Participant three: *"No. I don't think it will really affect me. My older sister will probably have to do more, as she has always been closer to (=name of sibling with autism=) and she is older so will know what to do". (p.3)*

The other participant commented that there had been improvements in his brother's condition as his brother had grown older. Therefore the participant felt that as time progressed the difficulties would subside and this participant felt things in the future would be better.

Interviewer: *"Do you think (insert name of sibling with autism) will affect your future?"*

Participant seven: *"No". (p.5)*

Interviewer: *"No?"*

Participant seven: *"No, things have got better as we have gotten older. So I think things might be better". (p.5)*

4.2.9   Theme nine: Acceptance and ambivalence

Throughout the data themes of 'acceptance' and 'ambivalence' emerged. Some participants (n=5) described that they had accepted

their brother and attempted to normalise aspects of the inter-sibling relationship or their own lived experiences. This level of acceptance may have been integral to their coping and subsequent adjustment. Many participants (n=10) described their brother in a positive and accepting manner. These participants accepted the impact their brother's condition had on their lives and their accounts consist of dialogue that suggests they attempt to normalise their situation. Such appraisals may reflect inherent aspects of their coping responses.

Participant one: *"There isn't really much of an effect, its normal for me. I have just grown up with it. I don't know any different. So it doesn't really affect me. Just kind of learn to accept it and learn to deal with it. Its understanding that they cannot help the way they are and just learning to accept it".* (p.2)

Participant two: *"I just accept him for who he is".* (p.4)

Participant five: *"I don't think about it because I have sort of just grown up with it. He's just my brother".* (p.5)

In contrast, a number of participants (n=8) were more ambivalent in their responses. They demonstrated a degree of acceptance but also that they were experiencing a level of dissatisfaction in their relationship with their brother, the way their brother's condition

impacted on their lives and the daily challenge of living with their brother. There was no consistent pattern in these accounts. However, these discrepancies between wanting change and being dissatisfied may have been central in emotional processing and cognitive restructuring, as a function of the interactions during the interview process. These discrepancies related to the impact of their brother's condition on their lives and constructions of the quality of the inter-sibling relationship. The instances of ambivalence may have reflected participants' attempts to make sense of their lived experiences. Many of these participants appeared to want a normal and close relationship with their brother, but their brother's behaviours frequently impacted on them in a negative manner (e.g., aggression directed at typical sibling, disruption to home life, negative impact on relationships with peers).

Participant one: "*Like we went to Portugal and (=name of sibling with autism=) has got this thing where he has to walk and pace, like when he puts something in the bin he has to walk further on and then come back. It's a bit like 'what are you doing'?*" (p.3).

Participant six: "*We get on fine (pause). Well most of the time anyway*". (p.2)

Participant seven: "*Well we sometimes fight. Sometimes we don't. We don't fight as much anymore though*". (p.3)

Participant nine: *"He is quite easy to live with (pause) now". (p.2)*

Participant eight: *"We get on with each other, but then there's getting on and there's getting on". (p.2)*

Participant ten: *"Most of time he is ok". (p. 2)*

Participant eleven: *"Sometimes it is ok and other times it can be really difficult". (p.2)*

Participant eleven: *"Like if they shout and say something like "I hate you" they don't necessarily mean it. It's mostly just about the autism". (p.3)*

Chapter Five

Discussion

This chapter cautiously discusses the findings from the current study. The findings are related to previous studies, which were discussed and critically evaluated in the literature review. The limitations of the research are discussed. Avenues for future research are identified.

The findings in the current study were qualitative and nine broad themes were prevalent and relevant across the data. Some of the findings support previous research in the field. New findings emerged, which contribute to the knowledge base.

5.1   Initial observations

The exploratory nature of the research provided typical adolescent siblings of children with autism to have the opportunity to express their views in an open and exploratory paradigm way. The shift away from deficit models, which have dominated the literature, enabled a comprehensive exploration of the constructions and phenomenological experiences of adolescent typical siblings of young people with a brother with autism. This exploratory paradigm allowed both positive and negative constructions to emerge. It is hoped that this research will create a greater balance in the literature and will address some of the inconsistencies yielded by pathology models of investigation.

The current study is one of the first studies in this field guided by family systems theory and ecological systems perspective. These theoretical frameworks were adopted to develop an understanding of the many factors, at different levels, that contribute to variability in typical siblings' constructions, perceptions and coping responses. As a result, the research generated some interesting findings and makes a valuable contribution to the limited qualitative research in the literature (e.g., Dellve et al., 2000; Mascha & Boucher, 2006; Benderix & Sivberg, 2007; Bachraz & Grace, 2009; Petalas et al., 2009).

The methodological issues outlined by previous authors (e.g., Stoneman, 1998, 2005; Hodapp et al., 2005; Petalas et al., 2009) were considered during the conceptualisation of the research. Where possible, these issues were addressed in the current study in order to enhance the validity of the findings.

Issues relating to family size, birth order, gender, heterogeneous grouping and age spacing were taken into account. Participants were recruited from a broad and varied parent population and ultimately the sample of participants that engaged with the research reflected this.

During the recruitment phase of the research children and young people aged eight to twenty were invited to participate in the research. However, following the random sampling phase, a more narrow age range of participants was recruited for the research. The typical sibling participants who ultimately engaged in the research were aged thirteen to nineteen. This is significant as the research ultimately focused on a

specific developmental phase (e.g., adolescence). This has several implications for the current study as there may be unique effects and stressors that account for variability in typical siblings' constructions, perceptions and coping responses during adolescence. As previously discussed in the literature review, adolescence reflects a period when conflict and rivalry declines, as do perceptions of warmth and closeness (Buhrmester & Furman 1990; Buhrmester, 1992; Cicirelli, 1995).

The findings from the current study indicate that having a brother with autism does not automatically signify that adolescent typical siblings will construct and perceive their brother, the inter-sibling relationship and their phenomenological experiences in a negative manner. Petalas et al. (2009) suggested that typical siblings' appraisals and phenomenological experiences may reflect aspects of their appraisal process, which has implications for perceptions of stress, coping and adjustment (Lazarus & Folkman, 1984). As typical siblings' constructions and perceptions form an integral component of their coping efforts, the findings suggest that not all typical siblings with a brother with autism will be automatically at risk for maladaptive adjustment.

There was significant variation between individual participants in terms of their constructions, perceptions and coping responses. This may reflect the significant variability in the presentation and severity of autism between individuals. All typical siblings identified some positive aspect of having a brother with autism, albeit to varying extents. Some typical siblings' described they had warm and affectionate inter-sibling

relationships with their brothers, where they engaged in mutual activities and shared interests and experiences. However, a minority of typical siblings described the daily issues they encountered. These typical siblings spoke about the negative impact of differential treatment, limited attention and disruption to many aspects of their lives, as well as being the target of extremely aggressive behaviours. These typical siblings described internalising and externalising difficulties and maladaptive coping strategies, such as avoidance and isolation. It may be that these individuals were at risk for maladaptive adjustment.

A number of complex interactive variables across a range of systems appeared to further influence typical siblings' constructions, perceptions and coping responses. These variables also appeared to be dynamic and subject to change across the life span. The exploratory findings in the current study indicate that typical siblings' constructions, perceptions, and coping responses are influenced by nine discrete themes.

5.2   Theme one: Knowledge and understanding of autism

Research suggests that providing children and young people with developmentally appropriate information can support them to develop resilience in the face of adversity (e.g., Harris, 1994; Glasberg, 2000; Harris & Glasberg, 2003).

Bibace and Walsh (1979, 1980) demonstrated that the developmental stage of children and young people is integral in informing their understanding of physical illness. This research was underpinned by a Piagetian framework. The authors suggest that children and young people typically advance through discrete stages of reasoning in relation to health and physical illness.

During the first stage, the authors suggest that children demonstrate incomprehension. This is then followed by 'phenomenism', where illness is attributed to an external cause (cited in Glasberg, 2000). This is then followed by 'contagion' where children view illness and cure as two discrete entities that are inherently interlinked.

Glasberg (2000) suggested "both illness and cure are seen as transmitted through physical contact, which is under the control of one's own behaviour" (p. 145). The author suggests that children can now attribute illness to more than one cause and appreciate that both illness and cure occur within the body.

As children develop formal operational reasoning abilities from age twelve to adulthood, Glasberg (2000) suggested a "psychophysiological understanding emerges" (p.145). During this stage young people become aware of the influence of the mind on the body, through both afferent and efferent neurological pathways.

In the current study the ways in which typical siblings constructed and understood 'autism' varied significantly between individuals. This may reflect differences in how typical siblings construct meaning based on

the variability between individuals in the severity and presentation of autism. However, the majority of typical siblings characterised their knowledge and understanding of autism in terms of psychophysiological characteristics. Participants described both psychological and behavioural impairments associated with the disorder, which is likely to be a function of their developmental stage, which supports previous research (e.g., Bibace & Walsh, 1979, 1980; Glasberg, 2000).

This theme has emerged in previous studies. Howlin (1988) demonstrated that the amount of information about ASD and open communication about the condition, was associated with more positive sibling adjustment.

Dellve et al. (2000) found that typical female siblings with greater knowledge and a more comprehensive understanding of their brother's disability (e.g., DAMP and Asperger's syndrome) was associated with greater acceptance and less embarrassment.

Glasberg (2000) examined how typical siblings develop an understanding of autism in a sample of sixty-three participants varying in age. The authors concluded that children's reasoning became more mature with age, but developed at a slower rate in comparison to norms for other illnesses.

In the current study a number of typical siblings described how they experienced difficulty explaining their brother's disability to friends, colleagues and the public.

Participant three: *"I have to sort of then explain about his difficulties with understanding and that. Lots of people just don't get it"*. *(p.3)*

Participant five: *"Most people don't really understand autism because it doesn't really affect them"*. *(p.4)*

Other typical siblings also described how they accepted their brothers' disability as a part of their brother.

Participant one: *"Its understanding that they cannot help the way they are and just learning to accept it"*. *(p.2)*

It is clear that typical siblings are placed under demands to provide comprehensive explanations to friends and the public. A number of typical siblings described feelings of frustration, embarrassment and anger when they were required to explain and justify their brother's disability.

Participant ten: *"It's annoying when people don't understand autism as well and they don't understand him"*. *(p.2)*

Participant ten: *"They think that he is like mentally disabled...some people think he is like a different species"*. *(p.3)*

Participant twelve: *"I wish people wouldn't look as much and stuff because it makes him worse and then I get really embarrassed". (p.4)*

It is evident that the findings in the current study support findings from previous studies (e.g., Dellve et al., 2000; Howlin et al., 2002; Harris & Glasberg, 2003). During adolescence typical siblings are capable of developing a comprehensive understanding of autism. The current study demonstrates that an accurate understanding of autism will support typical siblings to develop acceptance. This understanding and knowledge is also important when typical siblings are placed under demands to explain the condition, which may be integral in reducing negative feelings such as frustration, embarrassment and anger. This may have important implications for typical sibling adjustment during adolescence.

5.3   Theme two: Perceptions

All typical siblings described their brother in a positive way, albeit to varying degrees. Typical siblings used terms such as "happy", "active", "brave" and "funny". These terms were often associated with positive experiences and positive interactions with their brother, as well as to characteristics of "warmth", "affection" and "closeness".

However, a minority of typical siblings described how the difficulties associated with their brothers' condition, such as impaired social

communication and behaviour difficulties, clouded their perceptions of their brothers. Typical siblings used terms, such as "aggressive", "withdrawn", "moody" and "temperamental". Some of these typical siblings indicated that they found it hard to engage in joint activities with their brothers and that it was difficult to communicate with them. This suggests they may have found it challenging to develop a positive relationship and close bond with their brothers, as a result of the impairments and behavioural difficulties associated with autism.

These themes have emerged in previous research and some authors (e.g., Taunt & Hastings, 2002; Mascha & Boucher, 2006; Petalas et al., 2009) posit that siblings' positive perceptions may support siblings to share positive experiences and develop a close inter-sibling bond, which has implications for coping and adjustment. Positive perceptions may buffer typical siblings against adversity and difficulties in the inter-sibling/family relationship, which can support the development of resilience.

Gold (1993) demonstrated that siblings' negative perceptions may be associated with maladaptive adjustment. The author demonstrated that male siblings of boys with autism who had negative perceptions of their brother gained higher scores on the Child Depression Inventory (CDI; Kovacs & Beck, 1977).

 A minority of typical siblings described their brothers as "attention seeking". The typical siblings indicated that their brothers received more attention from parents, which may have contributed to their

negative perceptions of their brothers. These findings support the earlier research of McHale et al. (1986). The authors identified that perceptions of parental favouritism directed toward the child with the disability and typical siblings' feelings of rejection were associated with more negative sibling relationships.

5.4   Theme three: The quality of the inter-sibling relationship

The ability of siblings to develop positive inter-sibling relationships is important, as the sibling relationship represents one of the most enduring relationships that children and young people experience (Kramer & Bank, 2005; Seltzer et al., 2005; Ross & Cuskelly, 2006).

Constructs such as "warmth" and "closeness" dictated the quality of the inter-sibling relationship in the current study. Spending time together and engaging in mutually enjoyable activities and experiences was also considered important for typical siblings who reported they had a positive relationship with their brothers. These findings support the work of Buhrmester and Furman (1990), who posited that positive inter-sibling relationships are characterised by constructs such as warmth and closeness. These findings support earlier research. Previous studies demonstrate that that majority of participants characterise quality of the inter-sibling relationship with their sibling with autism in a positive manner (Roeyers & Mycke, 1995; Kaminski & Dewey, 2001; Barr, et al., 2008). In these studies contextual factors, such as sharing positive

experiences and spending time engaging in joint activities appeared to foster the development of positive inter-sibling relationships. As previously mentioned, this finding was replicated in the current study.

A minority of participants constructed the inter-sibling relationship more negatively and described how their relationship lacked in warmth and closeness. These siblings described that they did not share common interests or engage in joint activities with their brother. Some participants described that their brother's impaired social communication made it challenging to form a bond and engage in joint activities.

Buhrmester and Furman (1990) demonstrated that perceptions of warmth and closeness tend to be higher during childhood and decrease during adolescence. It was challenging to disentangle whether perceptions of warmth and closeness changed as a function of development, as this was beyond the scope of the current study. However, one participant noted that she placed less emphasis on her relationship with her brother and was less concerned about the difficulties she experienced at home, as a result of increased emphasis on the importance of her relationships with peers outside the family home. This finding supports earlier research in the literature (e.g., Buhrmester & Furman, 1990; Cicirelli, 1995).

Researchers suggest that the inter-sibling relationship tends to be asymmetrical during childhood with the older sibling supporting with the development and care of the younger sibling (Buhrmester &

Furman, 1990; Stoneman, 2001). In the current study, the majority of older siblings described that their relationship with their younger sibling remained asymmetrical. They attributed this to the fact that they were required to support and care for their younger brother. This supports previous research in the literature (e.g., Stoneman, 2001). There were instances of 'role crossover' in the current study, where younger typical siblings assumed more dominant roles. This finding is supported by previous research in the literature (e.g., Brody et al., 1991; Eisenburg et al., 1998; Hannah & Midlarsky, 2005; Smith, 2010).

5.5 Theme four: The impact of their brother's condition

All typical siblings described that having a brother with autism had some positive or negative impact on their lives, albeit to varying degrees.

A large proportion of typical siblings described that their brother had a negative impact on their lives. This appeared to result from difficulties siblings encountered introducing friends into the family home and maintaining relationships with peers. This finding has been described in previous studies (e.g., Kaminsky & Dewey, 2001; Hastings, 2003a). It may even be the case that concerns about peer rejection increase as children advance into adolescence in line with group socialisation theory (Harris, 1995), where adolescents place an increased emphasis on group conformity and rejection. This has significant implications as Buhrmester (1992) posited that adolescents who experience rejection

from their peers experience increased internalising difficulties (e.g., anxiety and depression).

Some siblings described feelings of embarrassment resulting from their brother's behaviours when venturing into the community.

A significant proportion of typical siblings commented that their sibling with autism had a negative impact on their family life and intra-familial relationships. Some typical siblings commented that differential parenting and attention, restrictions on activities, reduced individual time with parents, increased interparental conflict and the burden of caretaking responsibilities had a negative impact on their family life. Reduced family time and attention was identified as having a negative impact on typical siblings in the current research. This theme is prevalent throughout the disability literature. Typical siblings of children with a range of disabilities frequently report that they spend less time engaging in family activities and have less individual time with parents. Researchers suggest this occurs as parents are required to give more attention and support to the child or young person with the disability (McHale, et al., 1986; McHale & Gamble, 1989; Lobato et al., 1991; Knott et al., 1995; Wolf et al., 1998; Heller et al., 1999; Burke & Montgomery, 2000; Dodd, 2004; Naylor & Prescott, 2004; Petalas et al., 2009). This is particularly relevant for typical siblings of children with autism. Koegel and LaZebnik (2004) demonstrated that children with autism engage in more programmes in comparison to children with other disabilities which impacts on the amount of time parents can

provide to the typical sibling. The authors proposed that as a result of the difficulties associated with autism, children require regular support and direction to engage in activities. This subsequently impacts on the time and attention parents can give to typical siblings.

Findings in the literature demonstrate that reduced family time/attention from parents elicits feelings of anger, isolation, low self-esteem, incompetence, resentment as well as perceptions of neglect in typical siblings (McHale & Pawletko, 1992; Powell & Gallagher, 1993; Meyer & Vadasy, 1994; Wolf et al., 1998). Typical siblings in the current study described how they experienced these feelings, particularly during early and middle childhood, but commented that these feelings had reduced as they progressed into adolescence.

In the current study one typical sibling described how she would actively attempt to excel in academic work and extracurricular activities in order to attempt to capture her parent's attention and compensate for her brother with autism. This finding has been described previously (Michaelis, 1980; Frank, 1996). Naylor and Prescott (2004) found that typical siblings reported they felt increased pressure to achieve in order to compensate for their sibling's disability. Seligman and Darling (1989) proposed feelings of increased pressure and a lack of recognition of individual achievement and attainment can have a lifelong impact on typical siblings.

The impact of differential treatment was identified as having a negative impact on typical siblings in the current research. This is a common

theme throughout the disability literature and typical siblings of children with a range of disabilities, including autism identified that differential treatment had a negative impact (Lobato et al., 1991; Corter et al., 1992; McHale & Pawletko, 1992; Furman, 1993; Fisman et al., 1998; Stoneman, 1998, 2005).

In the current study typical siblings described how differential behavioural management impacted on them and this finding has been described previously. Banks et al. (2001) demonstrated typical siblings reported feelings of resentment and uncertainty when punitive action was not taken against their brother or sister with autism. This was found to be especially salient when parents were less tolerant of the behaviours of typical siblings (Foster et al., 2001).

A number of studies suggest that parents of siblings with a disability report increased stress (Cuskelly et al., 1998; Fisman et al., 1996, 2000; VanRiper, 2000; Dyson, 2003). Perceptions of increased stress may result in increased interparental conflict. One typical sibling described that she became 'triangulated' in inter-parental conflict. This theme has been demonstrated in the literature (Rodrigue et al., 1993; Stoneman, 2001; Rivers & Stoneman, 2003). Nixon and Cummings (1991) demonstrated typical siblings of disabled children were more sensitised to everyday family stresses, such as interparental conflict and frequently displayed increased perceptions of threat, emotional distress, personal responsibility and involvement which resulted in increased adjustment difficulties.

Some typical siblings also spoke of the adverse impact of caretaking roles and responsibilities on their family life. This has been demonstrated as a source of stress extensively in the literature (Stoneman et al., 1991; Coleby, 1995; Cuskelly & Gunn, 2003; Harris & Glasberg, 2003; Stoneman, 2005). 'Parentification' of a child can result in maladaptive adjustment, poor self concept and the inability to form secure and lasting relationships during adulthood (Chase, 1999).

An ecological systems perspective enabled a degree of exploration of the impact on typical siblings' education. This finding has not previously been examined in the literature and these findings make a contribution to the evidence base. Conversely the majority of typical siblings reported their brother had a negative impact on their education and school experiences. This appeared to be a function of 'spill over' effects resulting from disruptions at home. One typical sibling described that his brother frequently experiences significant difficulties attending school on a Monday as a result in the change in routine following the weekend. This frequently resulted in increased conflict at home and this impacted on the typical sibling's ability to focus and concentrate in school. Another sibling described that her brother disrupted her sleep, which had a negative impact on her attendance. Other typical siblings described how disruptions at home affected their ability to complete home work and revise, which resulted in appraisals of increased stress.

A minority of typical siblings described how they experienced feelings of embarrassment, particularly if they attended the same school as their

brother and this had a negative impact on their ability to form and maintain relationships with peers. This finding has been described in previous research (Royers & Mycke, 1995; Opperman & Alant, 2003; Petalas et al., 2009). Further research is needed to clarify the ways in which typical siblings' education and academic attainment is affected by having a sibling with autism throughout development.

A proportion of typical siblings described feelings of grief or loss. Some typical siblings expressed that on occasions, they contrasted their experience of having a brother with autism with their peers' typical sibling relationships and felt a sense of sorrow and loss as they realised they would never share some of these experiences with their brother with autism. This finding has been replicated in previous studies (e.g., Harris & Glasberg, 2003) who suggest that typical siblings sometimes feel as though they need to excel in their own lives to compensate for their disabled sibling's difficulties.

In contrast, typical siblings also described that having a brother with autism had a positive impact on their lives. Some siblings described their familial and inter-sibling relationships as characterised by increased strength and closeness as a result of their brother's condition. This supports findings in the disability literature. Typical siblings of children with learning disabilities and ASD described their familial relationships as warmer and closer in comparison to typical siblings (Lardieri et al., 2000; Mascha & Boucher, 2006).

A minority of typical siblings commented how their brother's special interests in mathematics and computing enhanced their own learning. This finding has not been identified in the literature.

Some typical siblings, who were all female, described how they took pleasure from caring and supporting the needs of their brother with autism. It may be that these participants were adopting a psudo-parental role. Two female participants were from single parent families and described that they supported their mothers in caring for their brothers. They described that they enjoyed adopting this role and supporting their brothers. This finding has not previously been evidenced in the disability literature and this may be the result of a lack of variability in demographic characteristics in samples of participants previously used in the literature. Gender roles change and evolve across development and during adolescence females place an increased emphasis on their role within the family, in comparison to males, which is linked to gender identity development (Crouter, Manke and McHale, 1995; McHale, Router & Whiteman, 2003).

An additional theme that emerged in the current study was typical siblings' perceptions of the impact of their brother's difficulties on their personal development and self concept. Self concept is a multidimensional construct and refers to an individual's perception of their 'self', which can be affected by a multitude of factors, such as gender, family characteristics and academic attainment (Shavelson & Bolus, 1982; Byrne, 1984; Byrne & Gavin, 1996; Wade, 1998; Bong &

Clark, 1999; Hoffman, Hattie & Borders, 2005). Self concept has important associations for self-esteem, which can affect individual adjustment (Fleming & Courtney, 1984). The findings in the research demonstrated that the majority of typical siblings considered that having a brother with autism had a positive impact on the formation of their self and their identity. Typical siblings described how their experiences had made them more "empathetic", "patient", "caring", "non-judgemental" and "emotionally stronger". One typical sibling reported she hoped to enter into a caring profession as a result of growing up with her brother and witnessing the ways in which professionals had helped and supported her brother. These findings are supported by research in the literature. A number of studies posit that siblings thrive as a result of having a brother or sister with a disability and are psychologically stronger as a result (Taunt & Hastings, 2002; Stoneman, 2005). Macks and Reeve (2007) demonstrated that typical siblings of children with autism had more positive self concept. Some authors suggest that typical siblings of children with disabilities, including autism, will be required to adopt a range of roles and compensate for their sibling's difficulties. This may enhance perspective taking, as well as the development of emotional literacy, social skills and positive self concept (Flavell, et al., 1968; Cuskelly & Gunn, 2003; Verte et al., 2003). The findings in the current study contradict the findings in the literature. Some authors suggest that typical siblings of children with autism demonstrated no differences in self concept or perceived

competence (Bagenholm & Gillberg, 1991; Bischoff & Tingstrom, 1991; Lynch, et al., 1993; Burton & Parks, 1994; Dyson, 1996; Hannah & Midlarsky, 1999; Fisman et al., 2000; McMahon, Noll, Michaund & Johnson, 2001; Singhi, Malhi & Dwarka, 2002; Verte et al., 2003).

A minority of typical siblings reported that their experiences had a negative impact on them. One typical sibling described that he was an "angry" person as a result of the stresses and demands placed upon him. Sharpe and Rossiter (2002) reported typical siblings of children with a chronic illness had more negative self concept, which had implications for their adjustment.

It may be that the aetiology of specific disabilities, such as autism, has specific implications for sibling-interactions, experiences and the roles typical siblings are required to adopt. Family resources may also impact on the roles typical siblings are required to assume. Further research is needed to clarify how children and young people's concepts of self develop in families where a child or young person has a disability, such as autism.

5.6   Theme five: Coping strategies

The typical siblings in the current study described that they used a variety of coping strategies in response to a variety of stressors. All participants identified specific stressors that affected them to different degrees, which included:

- differential treatment;

- reduced attention from parents;

- difficulties with peers;

- requirement to mediate to reduce inter-sibling conflict;

- inter-parental conflict;

- disruption to home life;

- embarrassment/social stigma; and

- physically/verbally aggressive behaviours directed at the typical sibling.

Investigation of the relationship between specific stressors and subsequent coping strategies was beyond the scope of the current research. This clearly warrants further investigation.

However, the current study did explore the strategies that typical siblings adopted in an attempt to cope with the aforementioned stressors, which was underpinned by theoretical frameworks proposed by Lazarus and Folkman (1984) and Weiten and Lloyd (2008).

Lazarus and Folkman (1984) developed a comprehensive theory of stress and coping, which has been applied to a range of disciplines (e.g., medicine, social science). The authors propose two concepts are significant in psychological stress:

- appraisal (e.g., an individual's evaluation of the significance of a specific stressor for their physical and psychological wellbeing); and

- coping (e.g., an individual's cognitive and practical efforts to manage demands).

In terms of this conceptualisation of 'stress', stress is not viewed as a specific trigger of pattern of psychological, behavioural or cognitive actions. Instead, stress refers to a transaction between individuals and their environment and stress will occur when an individual appraises a stimulus as significant for wellbeing and when the demands exceed coping resources (Lazarus, 1993).

Lazarus and Folkman, (1984) and Weiten and Lloyd (2008) suggest that individuals employ one strategy, or a combination of strategies to cope when they appraise a stimulus as 'stressful', such as:

- problem focused strategies;

- appraisal focused strategies; and/or

- emotion focused strategies.

This theory is helpful in explaining variations in perceptions of stress and coping response. Lazarus and Folkman (1984) posit that no event or situation is inherently stressful and it will not evoke a consistent response. Instead perceptions of stress are based on an individual's

appraisal of a stimulus as potentially harmful, threatening or demanding.

As previously mentioned in the review of the literature, Brougham et al. (2009) suggested problem focused coping strategies result in improved physical health and wellbeing, as well as improvements in self-esteem. Conversely emotion focused coping strategies can result in maladaptive adjustment, cognitive deficits, physical illness, poor self concept and sleep disturbances (Brougham et al., 2009).

In the current study, the majority of typical siblings used a combination of all three coping strategies, which supports previous studies in the literature (e.g., Taylor, 2006). For less significant stressors some typical siblings described they used problem focused coping strategies in an attempt to adapt or modify their own behaviour (e.g., increasing their knowledge of autism, learning behaviour management techniques).

A minority of typical siblings who were the target of severe aggression or required to intervene to manage their brother's violent behaviours, described how they adopted emotion focused strategies, such as isolation or avoidance. These siblings described that they felt "depressed", "upset", "isolated", "angry" and "frustrated". This subgroup may be at risk for maladaptive adjustment. This finding has been demonstrated previously. Ross and Cuskelly (2006) found that typical siblings of children with ASD commonly used emotion focused strategies to cope in response to stress. The authors also found that

typical siblings' knowledge of autism was important in mediating their stress response.

This warrants further investigation. Petalas et al. (2009) commented that "there has been little research systematically exploring children's coping strategies in the context of having a sibling with ASD" (p.394). The author proposes that positive perceptions may mediate the relationship between adjustment and coping. There is some evidence in the findings in the current study that suggest typical siblings who perceived their brother in a more positive manner were more forgiving and used more adaptive coping strategies. Further research is needed to explore individual variability in coping.

5.7   Theme six: Perceptions of others

The majority of typical siblings who participated in the current study described that they experienced difficulties when venturing into the community. A small minority of typical siblings expressed that they encountered positive experiences in the community and felt that their brother's needs and difficulties were understood.

Typical siblings described a range of negative experiences as a result of the impact of people's perceptions in the community, which led to feelings of frustration and embarrassment. A minority of typical siblings described that they were frequently required to take defensive action

to support their brothers. Other typical siblings described they worried about their brother venturing into the community.

Some typical siblings described they deliberately felt isolated as a result of their brother's difficulties. This often impacted on the family and restricted family activities.

Bagenholm and Gillberg (1991) found that typical siblings of children with autism reported feelings of increased loneliness and social isolation as a result of their sibling with autism.

Petalas et al. (2009) identified typical siblings encountered negative reactions and stigma from individuals in the community and peers, which resulted in feelings of embarrassment, frustration and anger. The authors reported that typical siblings in middle childhood described prejudice and a lack of understanding and empathy from the public. Other studies in the literature support these findings (e.g., Royers & Mycke, 1995; Opperman & Alant, 2003).

Typical siblings also described they experienced difficulty explaining their brother's condition or unusual behaviours (e.g., flapping). A minority of typical siblings even withdrew and isolated themselves in order to avoid the burden of providing an explanation to the public.

A number of typical siblings commented that autism is a complex disability. Children and young people with autism do not have distinct physiological markers that enable the public to acknowledge that a child with autism has a disability. This added to siblings' difficulties in

providing explanations to peers and members of the public. This finding has not been previously discussed in the literature.

5.8   Theme seven: Support

The current study briefly explored typical siblings' experiences of support in a qualitative paradigm, which has not previously been examined in the literature. Typical siblings frequently described that they accessed informal support from friends and family in response to events or stimuli they appraised as stressful. Typical siblings emphasised it was helpful to discuss difficulties with a member of their immediate family as they considered those individuals would share an understanding of the situation.

Other typical siblings described how they benefited from accessing formal support, such as individual counselling and sibling support groups.

Whilst two male typical siblings described they did not feel the need to access any form of support, every other typical sibling who engaged in the current study identified that support services for typical siblings of children with autism were lacking. This is significant, as services are clearly important in enabling adaptive and effective coping for typical siblings who may be encountering significant stress.

Morris (1998) proposed that support services for typical siblings from families with a disabled child are not frequently available and services

have typically been arranged for the disabled child (e.g., respite) through a process of separating the child with the disability from the family.

Nationally, there is increased recognition of the need for support services for typical siblings of children and young people with autism. However, most of the typical siblings who participated in the current study had no experience of formal support services and a number of typical siblings identified that this was something that could have helped to support them during stressful periods. As a result of the unique difficulties typical siblings of children with autism face, it is clear that more specialist provisions are required. Typical siblings were encouraged to consider support services that they perceived could be helpful for them in the current research. Typical siblings identified the following provisions would help:

- support groups for typical siblings of children with autism;

- education to improve their knowledge and understanding of autism;

- individual therapy/counselling;

- advice and strategies to manage behaviour problems;

- respite to give typical siblings more time with parents; and

- awareness raising and campaigns to educate the public and reduce stigma.

The majority of typical siblings considered that respite services and support groups would be most helpful and these themes were prevalent throughout the data.

These findings have been described in the literature. Bagenholm and Gillberg (1991) reported that typical siblings of children with disabilities felt they could only discuss their concerns with someone outside the home in an attempt to reduce burdening family members with additional stress.

Wolf et al. (1998) described the importance of securing a supportive relationship for typically developing siblings outside the context of a stressful family system for siblings of children with pervasive developmental disorder.

Evans, Jones and Mansell (2001) explored the effectiveness of support groups for typical siblings of children with learning disabilities and challenging behaviour. The authors demonstrated that typical siblings benefited from the experience of increasing their knowledge and understanding, which resulted in increased involvement and improvements in self-esteem.

Petalas et al. (2009) described that typical siblings of children with autism in middle childhood had limited experiences of support services. The authors propose that typical siblings typically accessed support from other typical siblings in the family, parents and professional services (e.g., respite and support groups).

Nixon and Cummings (1999) posited that siblings of children with disabilities may be sensitised to everyday family stress (e.g., emotional distress, expectations of involvement, perceived threat and responsibility, lower thresholds for conflict intensity, maladaptive adjustment). The authors suggested that further research is needed to ensure typical siblings of children with disabilities, including autism, are provided with formal support services that meet typical siblings' needs. Generic support services for typical siblings of children with disabilities may neglect to account for specific difficulties that typical siblings encounter as a result of specific aetiological differences in disabilities. Further research is needed to clarify what types of support services typical siblings of children and young people with autism require, as a result of the unique aetiological features associated with autism. Typical siblings' need for formal support services may also vary as a result of their development. Formal support services should recognise that children's and young people's needs are likely to vary in response to their developmental stage.

5.9   Theme eight: The future

A prevalent theme throughout the current study was related to typical siblings' concerns about the future. The majority of typical siblings described they were concerned about the burden of future caring responsibilities, as well as the impact on their own lives and

independence. Typical siblings commented that their concerns about future responsibilities had increased as they progressed through adolescence. This may have resulted from a recognition of their own parents' mortality as well as recognition that their own independence may be affected in the future. This finding has been demonstrated previously. Harris and Glasberg (2003) suggested adolescence is a time when typical siblings may begin to experience concerns about the future and about long-term provision.

Female siblings who were older than their sibling with autism expressed significant concerns about the future. A minority of typical female siblings commented they felt positive with respect to future caretaking responsibilities.

These findings have been demonstrated in the disability literature. Bagenholm and Gillberg (1991) demonstrated typical siblings of children with autism appeared more concerned about the future in comparison with other participants.

Kaminski and Dewey (2002) examined the psychosocial adjustment of thirty typical siblings of children with autism, thirty typical siblings of children with Down syndrome and thirty typical siblings of normally developing children. The authors demonstrated that typical siblings expressed fewer concerns about future caring responsibilities when they were from larger families.

These findings have significant implications. McHale et al. (1986) demonstrated that typical siblings experienced more positive

174

relationships with their sibling with a disability when they had no concerns about the future.

5.10   Theme nine: Acceptance and ambivalence

Throughout all aspects of the current study themes of 'acceptance' and 'ambivalence' were prominent. In the current study many typical siblings accepted their brother's condition and the impact this had on their lives. There was no clear association between typical siblings' accounts and their lived experiences. However, a number of typical siblings who frequently encountered significant stress tended to describe their situation in a more ambivalent manner. This supports findings in the literature.

Opperman and Alant (2003) identified high rates of ambivalent feelings in adolescent participants of children with severe disabilities. The authors propose this may have reflected participants' attempts to actively regulate stress and negative emotions in order to cope with their situation.

More recently, Petalas et al. (2009) described that typical siblings of children in middle childhood expressed "divergent attitudes towards their brother with ASD" (p.393). The authors propose that some participants accepted their circumstances, whilst others demonstrated a clear desire for change. Petalas et al. (2009) suggested there may be a

relationship between ambivalent accounts and adjustment difficulties and emphasise that more research is needed to clarify this.

5.11   The role of constellation variables

As discussed in the review of the literature, a number of 'constellation' variables are proposed to influence perceptions of inter-sibling relationship quality in dyads when a child or young person has a disability (Smith, 2010, p.16). Buhrmester (1992) suggested these variables include gender, birth order and age spacing. Due to the limited scope of the current study the impact of these variables was not directly examined. However, a number of pertinent observations were made.

In terms of sibling gender, the findings in the literature are fairly inconsistent and contradictory (Smith, 2010). There was no clear impact of child gender in the current research. In terms of gender typical female siblings tend to report higher levels of warmth and closeness in same-sex female dyads in comparison to same-sex male dyads (Furman & Buhrmester, 1985). Female dyads also tend to report increased intimacy, companionship, admiration and similarity in comparison to male dyads (Buhrmester & Furman, 1990). The perception of typical siblings in same-sex dyads was not explored as the research design attempted to control for the role of gender variables by using a sample of male siblings with autism. Although there was not a clear impact of gender in relation to typical siblings' perceptions, some male

participants described their relationship with their brother as 'close'. Over half the female participants expressed that they perceived their brother as "isolated", "distant" or "in his own world". This may reflect the fact that female typical siblings were attempting to develop close and intimate inter-sibling relationships with their brother. However, their brothers' impairments in social-communication and language may have impacted on female typical siblings' abilities to achieve this type of relationship with their brothers.

In the disability literature some research suggests that boys engage in more caring or altruistic behaviours to support the needs of their sibling with a disability in comparison to typical sibling dyads. The literature also suggests that sisters of children with a disability appear to adopt more nurturing and supportive roles to support the needs of their sibling with a disability (Brody et al., 1991; Stoneman et al., 1991; Hannah & Midlarsky, 2005). Some research has challenged these findings and suggests there are no significant differences in the roles as a function of typical sibling gender (Cuskelly & Gunn, 2003).

In the current study the majority of typical siblings described they adopted caring or supportive roles to support the needs of their brother with autism to varying degrees. There appeared to be no difference as a function of typical sibling gender. As previously mentioned, typical female siblings in single parent families took on a larger proportion of caretaking roles in comparison to other families in the research.

However, it is difficult to draw accurate conclusions as no male typical siblings from single parent families participated in the study.

Birth order has also been found to impact on the quality of the inter-sibling relationship and individual adjustment. Older typical siblings of children with disabilities often report increased dominance over younger siblings (Smith, 2010). Younger siblings report greater admiration of their older sibling (Buhrmester & Furman, 1990). The literature suggests that birth order does not appear to influence levels of conflict and rivalry, which appear to be moderated by differential parental treatment. Older siblings report their relationships are more conflicted when they perceive younger siblings are favoured more by parents (Buhrmester & Furman, 1990; Kowal & Kramer, 1997). These findings were not evident in the current study. However, older typical siblings appeared to be more concerned about future caring responsibilities compared to younger typical siblings in the same family.

Age spacing among typical sibling dyads appears to exert consistent effect across the constructs of warmth, closeness, status, conflict and rivalry (Smith, 2010). Buhrmester and Furman (1990) proposed children report increased warmth, closeness, affection, prosocial behaviour, admiration but less intimacy in wider spaced (four or more years) dyads, compared to narrow spaced dyads (less than three years). In terms of status, older siblings in wider spaced dyads reported the greatest amount of nurturance and caring, as well as the highest levels of admiration by younger siblings (Buhrmester & Furman, 1990). Increased

levels of dominance were reported in narrow spaced dyads and conflict and competition were reported to be highest in narrow spaced dyads (Buhrmester and Furman, 1990). In the current study there were no consistent effects of age spacing which is consistent with previous research in the literature (Smith, 2010). There was some evidence however, for 'role crossover' and asymmetry, which occurs when younger typical siblings of children with a disability adopt more caring and altruistic roles in comparison to typical sibling dyads (Stoneman et al., 1991; Hannah & Midlarsky, 2005). Typical siblings of children with a disability frequently adopt more dominant roles to support the needs of their sibling with a disability (Stoneman, 2005). This effect appears to occur irrespective of the age of the typical sibling. Older and younger typical siblings of children with disabilities frequently adopt more dominant roles to support the needs of the sibling with a disability, irrespective of the developmental stage of the child or young person with a disability (McHale & Gamble, 1989; Stoneman et al., 1991; Cuskelly & Gunn, 2003).

In the current study all typical siblings spoke of adopting some form of caring role. Typical siblings who were younger than their brother described how they frequently supported their brother by providing care, teaching and behaviour management irrespective of the severity of their brother's disability. This provides evidence for non-normative role relations of adolescent typical siblings of young people with autism. This asymmetry did not appear to have a negative effect on sibling

perceptions of the overall quality of the sibling relationship, as demonstrated in previous research (e.g., Smith, 2010).

The findings in the current study also demonstrated how younger siblings experienced role 'crossover'. Younger typical siblings frequently described that they supported the learning of their brother and appeared to assume more dominant roles, as demonstrated in previous studies (Brody et al., 1991; Stoneman et at., 1991; Dallas et al., 1993). However, a minority of typical siblings described how their brother supported their own learning and development. This finding occurred irrespective of the relative age of typical siblings and reflects a new finding in the literature.

Stoneman (2005) suggested that it is important to consider how the age of the typical sibling and the age of the sibling with a disability impacts on interactions and inter-sibling relationship quality. The author suggested that it is important to understand how the nature of the sibling relationship is characterised at different developmental stages, such as adolescence. In the current study the majority of typical siblings expressed they were more concerned about differential treatment and attention when they were in middle childhood. Some typical siblings also reported that as they advanced through adolescence, they grew increasingly concerned about the future. This finding has been described by Harris and Glasberg (2003). It is clear from these findings that the developmental stages of participants and their cognitive ability can influence their constructions and appraisals of stressors.

5.12   Limitations of the study

The current study produced some interesting findings that support previous research in the literature. The research also generated some new findings which contribute to the field. However, there are some limitations and the findings should be interpreted with caution.

Several authors have voiced concerns about methodological issues in the literature. These criticisms relate to inadequate control of extraneous variables, small sample sizes, homogenous groups of children and young people with a range of disabilities and discrepancies in the conceptualisation of dependent variables (e.g., adjustment), as well as disparities in measurement (e.g., Hoddapp et al., 2005; Stoneman, 2005; Petalas et al., 2009).

In the current study attempts were made to control for the impact of a number of extraneous variables (e.g., family size, developmental stage of both siblings, heterogeneous groupings of participants, age spacing between siblings). Young people with autism had to have a formal diagnosis of autism and had to be resident in the family home at all times.

There was a degree of variability in terms of socio-economic characteristics of the families who engaged with the research and in terms of family characteristics (e.g., single parents), which provides a degree of evidence for a level of diversity within the sample. There was also a relatively equal gender balance in the sample.

No typical siblings had any special needs/ medical issues or disabilities. It was important to ensure that all participants had a good level of receptive and expressive language to contribute to the research.

Retention was excellent throughout the research and no typical siblings or families chose to disengage at any stage of the research process.

Nevertheless, there are a number of limitations associated with the current research. The sample size was adequate to address the research question in a qualitative paradigm. However, the sample size was small in comparison to large-scale quantitative studies that are described in the literature. This reflects a limitation.

A total of twelve typical siblings participated in the research and although there was a degree of variability in demographic characteristics, such as gender and ethnicity, the sample was limited in the degree to which it represents that parent population.

Although a random sampling procedure was adopted in an attempt to ensure the sample would be generalisable to the parent population, there was a degree of bias in the sample. The majority of typical sibling participants were adolescents, Caucasian and lived in the West Midlands or South Wales. The majority of typical siblings (66%) were older than their brother with autism. Also there was a bias in age spacing between siblings. The vast majority of participants came from two-parent families. This has significant implications for the generalisability of the findings to single-parent families, who may be placed under increased stress.

There was a further bias in family characteristics and the majority of families contained two young people (i.e., the typical sibling and the young person with autism). This has implications for the generalisability of the findings to families containing more than two children or young people, as researchers (e.g., Harris & Glasberg, 2003; Stoneman, 2005) have demonstrated that larger family size can buffer typical siblings against the impact of having a sibling with autism.

Furthermore, the participants were recruited through a range of sources/gatekeepers (e.g., schools, local authority ASD coordinators and voluntary sector organisations). Traditionally, participants in the disability literature tend to be recruited through parenting groups or clinics (e.g., Dyson, 1996; Kaminsky & Dewey, 2002; Lobato & Kao, 2002), which results in a bias in the sample. Although attempts were made to recruit participants from a range of sources, it is possible that there was a degree of bias in sample. The largest group of participants (43%) were recruited through ASD Coordinators in local education authorities. This is significant as these families may have been receiving a higher level of support compared to other families. Also, the needs of the young people with autism in these families may have differed compared to other children and young people not known to the ASD coordinators. Also, all gatekeepers were required to select families on the basis of the inclusion criteria. Gatekeepers did not adopt any sampling procedures and may have been bias in their choices. This reflects a significant limitation in the current research.

Families were required to volunteer to participate in the research. This may have created a selection bias amongst participants and their responses may differ from those parents who chose to opt out of the research.

A number of studies demonstrate increasing evidence in support of a genetic basis for the aetiology of autism (Bailey et al., 1995; Piven et al., 1997; Piven, 1999; Pickles et al., 2000; Rutter, 2000). In previous studies (e.g., Benson & Karlof, 2008), attempts have been made to explore the role of the BAP in order to assess whether typical siblings may be at increased risk for difficulties. As a result of qualitative design of the current study, it was beyond the scope of the research to address this issue. Therefore, some typical siblings who participated in the research may have shared some of the impairments associated with autism to a lesser extent, as a function of the BAP. This has significant implications for inter-sibling interactions, social communication, and the development of positive inter-sibling relationships. Furthermore these siblings may have been constructing meaning from their phenomenological experiences in a different way to those participants who were 'typically developing'. This reflects a limitation in the research and threatens the validity of the findings.

The role of reflexivity in qualitative research is well established. Watt (2007) suggests that the concept of reflexivity is considered to be critical in facilitating an understanding of the phenomenon under study, as well as the research process. Given the complexity of field under study,

as well the nature of qualitative enquiry, the concept of reflexivity should have been addressed in the current research.

Attempts were made to ensure the semi-structured interview format was robust and addressed the research question. Moyson and Roeyers (2011) described that there is no standardised instrument which conceptualises and measures typical sibling adjustment. Therefore a decision was taken to use an open-ended semi-structured interview. Attempts were made to ensure the semi-structured interview addressed the research question and its design was informed by interview formats used in previous qualitative studies (e.g., Bachraz & Grace, 2006; Benderix & Sivberg, 2007; Petalas et al. 2009). The format of the semi-structured interview enabled the researcher to retain a level of consistency between interviews, thus making the semi-structured interview more robust. A pilot interview was conducted to ensure the questions addressed the research question and the format was accessible for the target sample. An independent researcher coded the transcripts in order to limit subjectivity.

However, there are a number of criticisms of 'soft' qualitative approaches in research. A standardised method of measurement was not employed and this poses a threat to the reliability and validity of the method of measurement. Attempts were made to record inter-coder percent agreement and this demonstrated the inter-coder reliability rate was more than adequate. However, the inter-coder agreement was

only calculated for a single transcript and not for the complete data set due to time constraints.

Furthermore, a hand coding system was used to enable themes to emerge from the data. This reflects a limitation in the current research. Pope, Ziebland and Mays (2000) suggested that the use of software packages, such as NVivo, can improve the accuracy of data analysis.

Patton (2001) advocates the use of 'triangulation' in qualitative research. Golafshani (2003) proposed that "triangulation is typically a strategy for improving the validity and reliability of research or evaluation of findings" (p.603). However, in the current study no attempts were made to triangulate the findings with data from other participants or sources (e.g., findings from siblings with autism). This poses a threat to the reliability and validity of the findings.

Also, participants' responses may have been influenced by experimenter bias (McCall & Simmons, 1969; Schaffir & Stebbins, 1991). Data collection, transcription and thematic analysis yielded a wealth of rich and valuable data. However, there are a number of limitations associated with the use of thematic analysis. The verbatim extracts must be used to illustrate a specific point or finding in response to the research question and evidence base. This is a difficult skill to master and is reliant on the researcher being constantly aware of the way in which meaning is being constructed from data. Some of the typical siblings expressed divergent attitudes, as previously discussed. This

presented a significant challenge in constructing meaning from the data and further complicated the process of thematic analysis.

Braun and Clarke (2006) acknowledged that it is extremely rare for a theme to be completely accurate or representative.

There are also associated limitations with a social constructionist perspective as opposed to adopting an essentialist/realist epistemological position to guide the search for knowledge. In the current study a social constructionist perspective was adopted and this enabled a broad exploration of a range of variables (Burr, 2003). Although this epistemological perspective is suitable for the current study this epistemological perspective does have some limitations. It often fails to ignore the interaction between biological/within child influences and broader context. An essentialist/realist approach may have facilitated a deeper exploration of uni-dimensional relationship between experience, meaning and language (Braun & Clarke, 2006).

Furthermore, a social constructionist perspective avoids a more linear positivist perspective, which supports the retention of a *meta* perspective. However, this also limits the ability of the researcher to draw accurate conclusions.

The construction of broad terms like 'autism', reflect a limitation in the current study. Rutter (2000) posited that although there is good evidence that suggests autism is a multifaceted disorder, a comprehensive understanding of the disorder has not yet been achieved. Until a comprehensive understanding of the disorder is

achieved, it is going to be challenging to understand how the disorder truly manifests in individuals and affects those in their immediate family.

There is also significant variation in the presentation and severity of autism between individuals. No attempts were made to examine how the severity of specific impairments impacted on typical siblings, as this was considered beyond the scope of the current research.

Despite the aforementioned limitations in the current research, the methodology was directed by the research question, epistemology and theoretical assumptions. There are limitations in all research. However, the chosen methodology was appropriate, as it addressed the research question and produced a wealth of rich data. This data were analysed and a number of findings emerged. These findings support a number of findings from previous studies in the literature. Some new findings emerged in the current study. Therefore this research clearly advances knowledge in the field. It is clear that this outcome was the result of a carefully conceptualised research paradigm, driven by an epistemological perspective that enabled the research question to be addressed.

Chapter Six

Conclusion

This chapter discusses the findings in relation to research and theory discussed in the review of the literature. The exploratory paradigm and qualitative nature of the research captured the voices of adolescent typical siblings of young people with autism. The study produced some interesting findings, which are supported by previous research in the literature. Some new findings also emerged, as a result of the thematic analysis that was employed. In this chapter the themes that emerged in the current study will be formulated into thematic models. These models will support practitioners to identify factors that support and impact on typical siblings' coping and adjustment. Avenues for future research will also be discussed. These findings are considered to be relevant to the field of educational psychology and practice. A primary role for EPs is to promote positive change for children and young people through the application of psychological theory, with a view to improving outcomes for all children and young people (Beaver, 2011). The current study demonstrates how the application of psychological theory can produce findings, which have implications for EP practice. These findings are also of relevance to other practitioners who provide assessments and support services to children and young people with autism and their families.

6.1 Adolescent typical siblings' constructions, perceptions and coping responses

The United Nations Convention on the Rights of the Child (1989) emphasised that children and young people have a right to be heard with respect to matters and decisions that affect them (Harding & Atkinson, 2009). The purpose of the current research was to move away from a pathology model to overcome the scientific inertia that has restricted the progression of research in this field (Stoneman, 1990).

The current research adopted a qualitative approach within an exploratory paradigm. Ecological systems theory and family systems theory aimed to develop an understanding of the factors that account for variability in typical sibling coping and adjustment.

Previous qualitative studies in this field (e.g., Mascha & Boucher, 2006; Benderix & Sivberg, 2007; Bachraz & Grace, 2009; Petalas et al., 2009), have provided typical siblings with the opportunity to express their views and feelings. The perspectives of typical siblings has traditionally been neglected in the literature, with the research 'lens' focusing on the inter-parental relationship or the child/young person with the disability (Stoneman, 2005; Bachraz & Grace, 2009; Petalas et al., 2009; Smith & Elder, 2010).

Deficit perspectives have also dominated the literature and this has perpetuated the assumption that all families with a child or young person with a disability will be placed under increased stress. This perspective also assumes that all family members will be placed at risk

for maladaptive adjustment (Weiss, 2002; Abedutto et al., 2004; Duarte, et al., 2005; Stoneman, 2005; Hastings et al., 2007; Herring et al., 2006). In more recent years, social models of disability have increasingly been adopted to explore how broader systemic factors impact on child development and adjustment (e.g., Bronfenbrenner, 1979). This paradigm shift has penetrated the disability literature.

As a result researchers have increasingly acknowledged that broader dynamic and static variables impact on typical children and young people with a sibling with autism (Cuskelly, 1999). However, findings to date are inconsistent (Benson & Karlof, 2008). Kaminski and Dewey (2002) described that children with autism typically present behaviours that can be extremely challenging for all members of the family, which may influence global family functioning and intra-familial interactions (Orsmond & Seltzer, 2007). As a result parents may also be placed under increased stress due to the demands placed on them by the child or young person with autism. This may affect their ability to provide adequate parenting to the typically developing child or young person (Morgan, 1988, cited in Pilowsky et al., 2004; Petalas et al., 2009; Smith & Elder, 2010). Rodrigue et al. (1993) emphasised that siblings may potentially have to cope with changes in family roles, activities and structure, feelings of shame and guilt, as well as loss of parental attention as a result of the unique demands associated with autism. A number of studies demonstrate increasing evidence in support of a genetic basis for the aetiology of autism (Bailey et al., 1995; Piven et al.,

1997; Piven, 1999; Pickles et al., 2000; Rutter, 2000). As a result of the interplay between the aforementioned genetic and environmental factors, typical siblings of children with autism may be placed at increased risk for adjustment difficulties. It is crucial that research in this field identifies the ways in which typical siblings of children with autism may be at increased risk for adjustment difficulties. Consideration should also be given to the many variables that moderate or mediate these effects (Labato, 1993, cited in Benson & Karlof, 2008).

The focus on the voice of the child in the current research has enabled an exploration of typical siblings' constrictions, perceptions and coping responses. In many cases typical siblings described positive aspects of having a brother with autism and many typical siblings described that they were able to form a close and warm inter-sibling bond, despite their brother's difficulties.

Petalas et al. (2009) proposed that typical siblings' personal accounts and perceptions may be closely associated with their appraisal process. Psychological theories on stress and coping (e.g., Lazarus & Folkman, 1984; Weiten & Lloyd, 2008) emphasise that appraisals of stressors and demands have significant implications for coping and adjustment.

As previously mentioned, family systems theory and ecological systems theory guided the current research. Nine themes emerged from this exploratory framework. There was a degree of variability between typical siblings' accounts, which may reflect the variability in the presentation and severity of autism between individuals.

However, a range of factors at different levels appeared to affect the ways in which adolescent typical siblings constructed, perceived and coped with having a brother with autism. Typical siblings described that a range of variables across different systems (e.g., inter-sibling, family, community) affected them in different ways. The interactions between these variables, across different systems may have significant implications for the formation of positive inter-sibling relationships and global family functioning. This ultimately has significant implications for adjustment outcomes for adolescent typical siblings of young people with autism.

The findings that emerged in the current study have been formulated into two models, which warrant further investigation. The first model illustrates the variables that support adolescent siblings of young people with autism to develop positive inter-sibling relationships and effective coping (Figure Three). The second model illustrates the variables that may impact on the ability of adolescent typical siblings of young people with autism to develop positive inter-sibling relationships and effective coping (Figure Four).
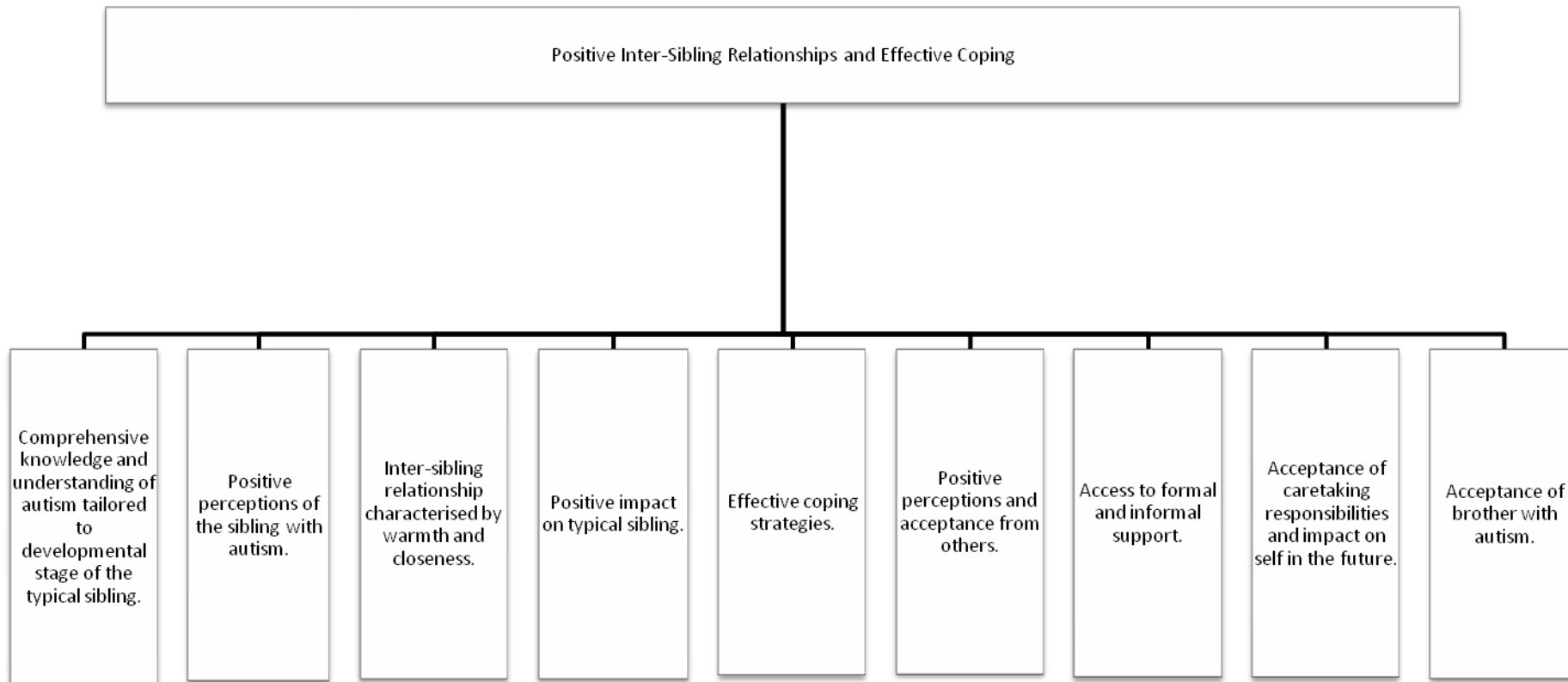
Figure Three: Proposed variables that support the development of positive inter-sibling relationships and effective coping for adolescent typical siblings with a brother with autism.
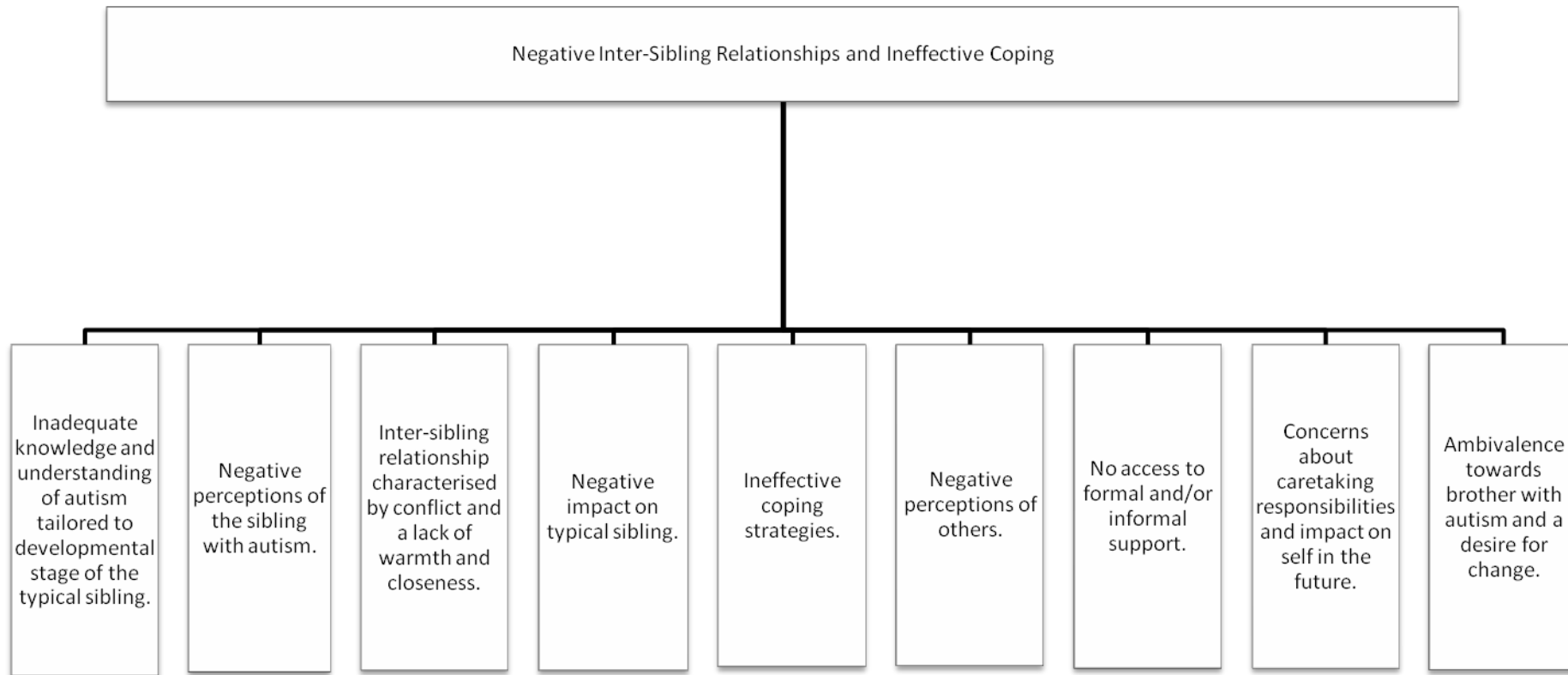
Figure Four: Proposed variables that prevent the development of inter-sibling relationships and effective coping for adolescent typical siblings with a brother with autism.

The exploratory nature of the research design facilitated a natural shift away from examining the ways in which static variables (e.g., gender, birth order, family size) account for variability in typical sibling adjustment. In the current study typical siblings naturally engaged in discourse around more dynamic factors, that they constructed as meaningful. Participants were able to describe both positive and negative experiences that had implications for their constructions, perceptions and coping responses.

The findings that emerged as a function of the thematic analysis are incorporated in the models (Figures Three and Four). The themes that emerged in the current study support findings from previous studies and make a valuable contribution to the field. The models demonstrate that a range of variables can foster the development of positive inter-sibling relationships and effective coping, which have clear implications for adjustment outcomes and global family functioning.

The current study was exploratory in nature. Clearly many more variables need to be incorporated into such models and the way in which some variables might mediate others needs exploring. This will support practitioners to develop a more comprehensive understanding of the variables that impact on typical siblings of children and young people with autism, across different developmental stages.

Further research in this field is needed to clarify how the themes presented in the current study generalise to the parent population. A significant amount of research is needed to develop a more

comprehensive understanding. However, the themes presented in the models (Figures One and Two) provide initial findings that may be used to inform assessment and support services for typical siblings of children and young people with autism.

6.2   Directions for future research

Ross and Cuskelly (2006) proposed that research in the field should focus on dynamic variables (e.g., coping skills, knowledge and understanding of autism), as these variables are more permeable to change. The authors suggest that research on the role of dynamic variables should be pursued further. A future direction would be to explore how specific stressors (e.g., severe inter-sibling conflict) are associated with coping and support seeking. This has clear implications for adjustment outcomes for typical siblings. Future designs should investigate these issues and use matched comparison groups of typical sibling dyads.

The current study gained more balanced accounts of positive and negative factors that contribute to typical siblings' perceptions and constructions in qualitative research paradigms. The use of pathology/deficit models in the disability literature may limit the extent to which findings accurately portray the phenomenological experiences of typical siblings of children and young people with autism. Future qualitative research is needed in order to develop a more

comprehensive understanding of how specific factors impact on typical siblings.

Stoneman (2005) suggested that researchers need to relinquish the negative attitudes and assumptions that have permeated the disability literature for so many years. A number of authors (e.g., Stoneman, 2005; Hodapp et al., 2006; Petalas et al., 2009) have criticised the methodological designs of a number of studies in the literature. Stoneman (2005) suggested future research designs need to employ large samples and multi-site studies of siblings, in longitudinal research designs. This will help to address how life course factors and the developmental stage of typical siblings and children and young people with autism impact on typical sibling adjustment over time.

Further research is needed to clarify how the severity and presentation of autism impacts on typical siblings and other family members. In the current research the adolescent typical siblings who appeared most affected were those who were the target of physical and verbal aggression on a daily basis. Therefore further research is needed to clarify how differences in the severity and presentation of autistic disorder impact on families in different ways.

Qualitative investigations could be adopted to investigate how dynamic and static factors mediate/moderate the relationship between having a sibling with autism and adjustment (Baron & Kenny, 1986).

Further research is needed to clarify how typical siblings' education and academic attainment is affected by having a sibling with autism

throughout development. Petalas et al. (2009) supported this and describes that "there has been little research systematically exploring childrens' coping strategies in the context of having a sibling with ASD" (p.394). Investigation of the relationship between specific stressors and subsequent coping strategies was beyond the scope of the current research. This clearly warrants further investigation.

Additional research is needed to clarify how children and young people's concepts of self develop in families where a child or young person has a disability, such as autism. This may buffer typical siblings against difficulties, which can foster the development of resilience.

The findings in the current research demonstrated that typical siblings who perceived their brother in a more positive manner were more forgiving and used more adaptive coping strategies. Positive perceptions form an integral component of typical siblings' appraisals (Lazarus & Folkman, 1984). This has implications for coping and adjustment. Further research is needed to explore the association between typical siblings' perceptions of their brother with autism and individual variability in coping.

Petalas et al. (2009) described that there is limited research in the literature on typical siblings' experiences of support. Although this was briefly explored in the current study, further research that incorporates the voices and perspectives of typical siblings of children and young people with autism is needed to clarify what types of support services typical siblings require. Future designs should consider how variability in

the severity and presentation of autism affects typical siblings' perceptions of the support they require. Also, the developmental stages of typical siblings should be taken into account when exploring this in future research, as children and young people's needs for support may vary as a function of their developmental stage.

The theme of ambivalence was prevalent and relevant in the current study. Typical siblings who experienced more difficulties in the inter-sibling relationship were observed to demonstrate more ambivalence in their accounts. Petalas et al. (2009) suggested that there may be a relationship between ambivalent accounts and adjustment difficulties. The authors suggested that additional research is needed to clarify this.

6.3 Implications for the role of the Educational Psychologist

Stoneman (2005) posited that "society has no greater task than to provide for the healthy positive development of children" (p.347). This is clearly a broader issue for legislators. However, this also has direct relevance for the role of the EP. The current research has some limitations and research in the field is still in its infancy (Cuskelly, 1999; Stoneman, 2005; Benson & Karlof, 2008; Petalas et al., 2009). However, the findings in the current study present initial evidence that have important implications for the role and practice of EPs, as well as other professionals who come into contact with children and young people with autism, typical siblings and families. The themes that emerged in

the current study could eventually be used to inform assessment and support services. However, future research is needed to further develop the thematic models presented in the current study.

EPs have a duty of care to all children and young people. EPs need to be aware of groups of individuals, such as typical siblings of children and young people with autism, who may be at an increased risk for difficulties as a result of the complex interaction between genetic vulnerabilities (e.g., the BAP) and environmental factors (Bailey et al., 1995; Piven et al., 1997; Piven, 1999; Pickles et al., 2000; Rutter, 2000).

Benson and Karlof (2008) suggested that although the majority of typical siblings are not placed at risk for adjustment difficulties, some typical siblings are at risk for difficulties as a result of stressors that arise from different systems (e.g., difficulties with peers). EPs often adopt *meta* perspectives in practice to enable the development of an understanding of the interplay between systemic factors at different levels. Therefore, EPs working with families with a child with autism need to be aware of the impact of the aetiological difficulties associated with autism, in order to intervene to provide comprehensive assessment and support services for typical siblings and families.

As discussed in the review of the literature, Knapp et al. (2009) concluded that the costs of supporting children with ASDs were estimated to be £2.7 billion each year. It is therefore crucial that practitioners in integrated children's services intervene as early as

possible, to support children with autism and their families to reduce the economic burden for society as a whole.

In line with this view EPs are ideally placed to work in consultation with other agencies to facilitate positive change for children and young people with autism, typical siblings and their families.

Fallon, Woods and Rooney (2010) argued that although there has been consistent debate about the role of the EP, both within and outside the profession, the main functions of the role are as follows:

> EPs are fundamentally scientist-practitioners who utilise, for the benefit of children and young people, psychological skills, knowledge and understanding through the functions of consultation, assessment, intervention research and training, at organisational, group or individual level across educational, community and care settings, with a variety of role partners (p.14).

Farrell et al. (2006) conducted a review of the function and contribution of EPs in light of the *Every Child Matter's Agenda* (DfES, 2003), which incorporates five core aims with a view of enabling all children to achieve their potential. The five core aims are as follows:

- stay safe;
- be healthy;

- enjoy and achieve;

- make a positive contribution; and

- achieve economic wellbeing.

The authors concluded that "EPs are in an excellent position to work with others in identifying gaps in services for children and in the planning and evaluation of new initiatives". (p.101). The findings in the current study demonstrate that typical siblings of children with autism may experience significant levels of stress and associated difficulties, which may impact on their adjustment. Farrell et al. (2006) stated that EPs can make a distinctive contribution in the work they undertake. EPs will be called upon to conduct statutory assessments of children and young people's special educational needs, as well as communicating and applying psychological knowledge to facilitate positive change and improve outcomes. In order to make a distinctive contribution and improve outcomes for children and young people in line with the *Every Child Matter's Agenda* (DfES, 2003), EPs need to consider how the needs of typical siblings, as well as children and young people with autism, can be best supported. The majority of typical siblings in the current research commented on the lack of support and provision. This finding has also been described by Petalas et al. (2000). In light of the conclusions drawn by Farrell et al. (2009), EPs are well placed to apply psychological theory to develop interventions and support services for typical siblings to foster the development of resilience.

A rise in mental health problems in children and young people has been observed in recent years (Rutter, 1991; Meltzer, 2005). Mackay (2006) argues this has direct relevance for the role of the EP. The author suggests that EPs work to address the needs of children and young people across a variety of contexts (e.g., home, school, community) in conjunction with other agencies.

The findings in the current study and the literature suggest a sub-group of typical siblings of children with autism may be at risk for adjustment difficulties (Kaminsky & Dewey, 2001; Hastings, 2003a; Rivers & Stoneman, 2003; Verte et al., 2003; Seltzer et al., 2004; Ross & Cuskelly, 2006; Orsmond & Seltzer, 2007). Therefore, EPs may be directly required to work with children and young people with these types of difficulties.

EPs need to recognise how specific factors (e.g., differential treatment, reduced parental attention, aggressive behaviour directed at the typical sibling) may place typical siblings at risk for maladaptive adjustment. Furthermore, an awareness of the impact of dynamic factors, such as coping and support, are crucial when developing policy, strategies and services for typical siblings and their families.

EPs may also have an integral role in action research which could inform the development of standardised assessment tools in the future. These assessment tools could potentially be used to identify typical siblings who may be at risk for developing adjustment difficulties.

A recent review of Child Adolescent Mental Health Services (CAMHS), conducted by the Department for Children, Schools and Families (DCSF; 2009), concluded that children and young people's mental health is everyone's business and all agencies working with children and young people in health, social care and education, have a role to play in contributing to the mental health and psychological wellbeing of all children and young people. As typical siblings of children with autism may be at risk for these difficulties, an awareness of individual, family and community risk factors is central to the role and practice of EPs.

In summary, the current study reflects a shift away from examining adjustment outcomes in typical siblings of children and young people with autism. It may be that a sub-group of children and young people may be at risk for maladaptive adjustment. However, the current study attempted to harness the voices of typical siblings in an attempt to understand their constructions, perceptions and coping responses. These findings have implications for EPs who may be required to assess how to intervene to provide support for children with autism, typical siblings and their families.

References

Abedduto, L., Seltzer, M.M., Shattuck, P., Krauss, M.W., Orsmond, G., & Murphy, M.M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109,* 237-254.

Abramovitch, R., Stanhope, L., Pepler, D., & Corter, C. (1987). The influence of Downs syndrome on sibling interaction. *Journal of Child Psychology and Psychiatry, 28,* 865-879.

Achenbach, T.M. (1991). *Manual for the child behaviour checklist/4018 and 1991 profiles.* Burlington, VT: University of Vermont Department of Psychiatry.

Albrecht, G., & Levy, J. (1981). *Constructing disabilities as social problems*, In Albrecht G (Ed.) *Cross national rehabilitation policies: A sociological perspective*. London: Sage

American Psychiatric Association (APA). (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th Ed.). Washington, DC: APA.

Antaki, C., Billig, M., Edwards, D., & Potter, J. (2002). Discourse analysis means doing analysis: A critique of six analytic shortcomings. *DAOL Discourse Analysis Online [Electronic Version], 1*(1).

Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report, 2,* 1-3.

Azmitia, M., & Hesser, J. (1993). Why siblings are important agents of cognitive development: A comparison of siblings and peers. *Child Development, 63*, 430-444.

Bachraz, V., & Grace, R. (2009). Creating a different kind of normal: parent and child perspectives on sibling relationships when one child in the family has autism spectrum disorder. *Contemporary Issues in early Childhood, 10,* 317-330.

Bagenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation. *Journal of Mental Deficiency Research, 35,* 291–307.

Bailey, A., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E., & Rutter, M. (1995). Autism as a strongly genetic disorder: Evidence from a British twin study. *Psychological Medicine, 25*, 63–78.

Banks, P., Cogan, N., Deeley, S., Hill, M., Riddell, S., & Tisdall, K. (2001). Seeing the invisible children and young people affected by disability. *Disability & Society, 16*, 797-814.

Bank, S., & Kahn, M. D. (1997). *The sibling bond*. New York: Basic Books.

Barbour, R.S. (2000). The role of qualitative research in broadening the 'evidence base' for clinical practice. *Journal of Evaluation in Clinical Practice, 6,* 155-163.

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173-1182.

Barr, J., McLeod, S., & Daniel, G. (2008). Siblings of children with speech impairment: Cavalry on the hill. *Language, Speech & Hearing Services in Schools, 39,* 21-32.

Beaver, R. (2011). *Educational Psychology Casework: A Practical Guide*. (2nd Ed.) London: Jessica Kingsley.

Begum, G., & Blatcher, J. (2011). The sibling relationship of adolescents with and without intellectual disabilities. *Research in Developmental Disabilities, 32,* 1580-1588.

Benderix, Y., Nordstrom, B., & Sivberg, B. (2006). Parents' experience of having a child with autism and learning disabilities living in a group home: a case study. *Autism, 10(6),* 629-41.

Benderix, Y., & Sivberg, B. (2007). Siblings' experiences of having a brother and sister with autism and mental retardation: A case study of 14 siblings from five families. *International Paediatric Nursing, 22,* 410-418.

Benson, B. A., Gross, A. M., & Kellulm, G. (1999).The siblings of children with craniofacial anomalies. *Children's Health Care, 28,* 51–68.

Benson, P.R., & Karlof, K.L. (2008). Child, parent, and family predicators of latter adjustment in siblings of children with autism. *Research in Autism Spectrum Disorders, 2,* 583-600.

Bernheimer, L.P. and Weisner, T.S. (2007). 'Let me just tell you what I do all day.' The family story at the centre of intervention research and practice. *Infants and Young Children, 20(3),* 192-201.

Bibace, R., & Walsh, M. E. (1980). Development of children's concepts of illness. *Pediatrics*, *66*, 912-917.

Bibace, R., & Walsh, M. (1979). Developmental stages in children's conceptions of illness. In G. C. Stone, F. Cohen & N. E. Adler (Eds.), *Health psychology* (pp. 285-301). San Francisco: Jossey-Bass.

Bischoff, L. B., & Tingstrom, D. H. (1991). Siblings of children with disabilities: Psychological and behavioural characteristics. *Counselling Psychology Quarterly, 4,* 311–321.

Bogden, R., & Biklen, S. K. (1992). *Qualitative Research for Education.* Boston: Allyn and Bacon.

Bong, M., & Clark, R. E. (1999). Comparison between self-concept and self-efficacy in academic motivation research. *Educational Psychologist, 34(3),* 139-153.

Boyatzis, R.E. 1998: *Transforming qualitative information: thematic analysis and code development*. London: Sage.

Brannon, L., & Feist, J. (2009). *Health Psychology: An Introduction to Behavior and Health.* Belmont, CA: Wadsworth.

Brask, B.H. (1972). *A prevalence investigation of childhood psychoses. Nordic Symposium on the Comprehensive Care of Psychotic Children.* Norway: Barne-Psykiatrisk Forening.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77-101.

Brody, G.H. (1998). Sibling relationship quality: Its causes and consequences. *Annual Reviews of UF Journals, 49,* 1-24.

Brody, G. H., Stoneman, Z., Davis, C. H., & Crapps. J. M. (1991). Observations of the role relations and behavior between older children with mental retardation and their younger siblings. *American Journal on Mental Retardation, 95,* 527–536.

Brody, G. H., Stoneman, Z., & MacKinnon, C. E. (1996). Contributions of maternal childrearing practices and play contexts to sibling interactions. *Journal of Applied Developmental Psychology, 7,* 225-236.

Brody, G. H., Stoneman, Z., & McCoy, J. K. (1994). Forecasting sibling relationships in early adolescence from child temperaments and family processes in middle childhood. *Child Development, 65,* 771 – 784.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22*, 723-742.

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*, 513-531.

Bronfenbrenner, U. and Morris, P. (1998). The ecology of developmental processes. In R. M. Lerner (Ed.), *Handbook of child psychology: Vol. 1. Theoretical models of human development.* New York: Wiley.

Brougham, R.R., Zail, C.M., Mendoza, C.M., Miller, J.R. (2009). Stress, sex differences, and coping strategies among college students. *Current Psychology, 28,* 85–97.

Buhrmester, D. (1992). The developmental courses of sibling and peer relationships. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues.* Hillsdale, NJ, England: Lawrence Erlbaum Associates, Inc.

Buhrmester, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development, 61,* 1387-1398.

Buist, K.L. (2010). Sibling Relationship Quality and Adolescent Delinquency: A Latent Growth Curve Approach. *Journal of Family Psychology, 24,* 400-410.

Burke, P., & Montgomery, S. (2000). Siblings of children with disabilities. *Journal of Learning Disabilities, 4*, 227-236.

Burr, Vivian (2003). *Social constructionism.* London: Routledge.

Burton, S. L., & Parks, A. L. (1994). Self-esteem, locus of control, and career aspirations of college-age siblings of individuals with disabilities. *Social Work Research, 18,* 178–185.

Buysse, V. and Wesley, P.W. (2005). *Consultation in Early Childhood Settings.* Baltimore, Maryland: Paul H. Brookes.

Byrne, B. M. (1984). The general/academic self-concept nomological network: A review of construct validation research. *Review of Educational Research, 54*, 427-456.

Byrne, B. M., & Worth Gavin, D. A. (1996). The Shavelson model revisited: Testing for the structure of academic self-concept across pre-, early, and late adolescents. *Journal of Educational Psychology, 88,* 215-228.

Campbell, T. (1996). Technology, multimedia, and qualitative research in education. *Journal of Research on Computing in Education, 30*(9), 122-133.

Carver, C. S., & Connor, S.J. (2010). Personality and coping. *Annual Review of Psychology, 61,* 679 - 704.

Cicirelli, V. G. (1995). *Sibling relationships across the life span.* New York: Springer.

Chase, N.D. (1999). *Burdened Children: Theory, Research, and Treatment of Parentification.* California: Sage.

Christensen, L., Hutman, T., Rozga, A., Young, G.S., Ozonoff, S., Rogers, S.J,…& Sigman, M. (2010). Play and developmental outcomes in infant siblings of children with autism. *Journal of Autism and Developmental Disorders*, *40(8),* 946-957.

Cohen, L., Manion, L., & Morrison, K. (2007). *Research Methods in Education.* Oxon: Routledge.

Cole, A., & Kerns, K. A. (2001). Perceptions of sibling qualities and activities in early adolescents. *Journal of Early Adolescence, 21*, 204-226.

Coleby, M. (1995). The school-aged siblings of children with disabilities. *Developmental Medicine and Child Neurology, 37,* 415–426.

Coon, D. & Mitterer, J. O. (2008). *Psychology: A Journey*. Belmont, CA: Wadsworth.

Cooper, H., Arber, S., Fee, L. and Ginn, J. (1999). *The Influence of Social Support and Social Capital on Health.* London, UK: Health Education Authority.

Corter, C., Pepler, D., Stanhope, L., & Abramovitch, R. (1992). Home observations of mothers and sibling dyads comprised of Down's syndrome and nonhandicapped children. *Canadian Journal of Behavioural Science, 24,* 1–13.

Costley, D. (2000). Collecting the views of young people with moderate learning difficulties. In A. Lewis & G. Lindsay (Eds.), *Researching children's perspectives.* Buckingham: Open University Press.

Cox, M.J. (2010). Family systems and sibling relationships. *Child Development Perspectives, 4,* 95-96.

Cox, M.J., & Paley, B. (2003). Understanding families as systems. *Current Directions in Psychological Science, 12,* 193-196.

Cox, M.J., & Paley, B. (1997). Families as systems. *Annual Review of Psychology, 48,* 243-267.

Crouter, A.C., Manke, B.A., & McHale, S.M. (1995). The family context and gender intensification during early adolescence. *Child Development, 66,* 317-329.

Cummings, E.M., Greene, A.L., & Karraker, K. L. (1991). *Life Span Psychology*. New Jersey: Lawrence Erblaum Associates Publishers.

Cuskelly, M. (1999). Adjustment of siblings of children with a disability: Methodological issues. *International journal for the advancement of counselling, 21,* 111-124.

Cuskelly, M., Chant, D., & Hayes, A. (1998). Behaviour problems in the siblings of children with Down syndrome: Associations with family responsibilities and parental stress. *International Journal of Disability, Development and Education, 45,* 259–311.

Cuskelly, M., & Dadds, M. (1992). Behavioural problems in children with Down's syndrome and their siblings. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 33,* 749–761.

Cuskelly, M., & Gunn, P. (2003). Sibling relationships of children with Down syndrome. *American Journal on Mental Retardation, 108,* 234–244.

Cuskelly, M., & Gunn, P. (1993). Maternal reports of behavior of siblings of children with Down syndrome. *American Journal on Mental Retardation, 97,* 521–529.

Dallas, E., Stevenson, J., & McGurk, H. (1993). Cerebral-palsied children's interactions with siblings—II. Interactional structure. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 34,* 649–671.

Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigor. *Qualitative Health research, 12*(2), 279-289.

Davis, M. C., Matthews, K. A., & Twamley, E. W. (1999). Is life more difficult on Mars or Venus? A metaanalytic review of sex differences in major and minor life events. *Annals of Behavioral Medicine, 21*, 83-97.

Del Rosario, B., & Keefe, E.B. (2003). Effects of sibling relationship with a child with severe disabilities on the child without disabilities: A review of research. *Developmental Disabilities Bulletin, 31,* 102-129.

Dellve, L., Cernerud, L., & Hallberg, L.R.M. (2000). Harmonizing dilemmas: Siblings of children with DAMP and Asperger's Syndrome experiences of coping with their life situations. *Scandinavian Journal of Caring Sciences, 14,* 172-178.

Department for Children, Schools and Families (DCSF). (2009). *Children and young people in mind: the final report of the National CAMHS Review.* London: DCSF.

Department for Education and Employment (DfEE) (2000). *Educational psychology services: Current role, good practice and future directions. Report of the working group.* London: DfEE.

Department for Education and Skills (DfES). (2003). *Every Child Matters (Green Paper).* London: HMSO.

Dodd, L. W. (2004). Supporting the siblings of young children with disabilities. *British Journal of Special Education*, *31*, 41.49.

Donovan, A.M. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal on Mental Retardation, 92,* 502-509.

Down, J.L. (1887). *On Some of the Mental Affections of Childhood and Youth.* London: Churchill.

Duarte, C.S., Bordin, I.A., Yagizi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism, 9,* 416-427.

Dykens, E. M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental Retardation, 43,* 360-364.

Dyson, L.L. (2003). Children with learning disabilities within the family context: A comparison with siblings in global self–concept, academic self–perception, and social competence. *Learning Disabilities Research and Practice, 18,* 1-9.

Dyson, L. L. (1996) Experiences of families of children with learning disabilities: Parental stress, family functioning, and sibling self-concept. *Journal of Learning Disabilities, 29,* 280–286.

Dyson, L. L. (1989). Adjustment of siblings of handicapped children: A comparison. *Journal of Paediatric Psychology, 14,* 215-229.

Eisenberg, L., Baker, B., & Blacher, J. (1998). Siblings of children with mental retardation living at home or in residential placement. *Journal of Child Psychology and Psychiatry, 39,* 355-363.

Evans, J., Jones, J., & Mansell, I. (2001). Supporting siblings: evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour. *Journal of Learning Disabilities, 5,* 69-78.

Fallon, K., Woods, K., & Rooney, S. (2010). A discussion of the developing role of educational psychologists within Children's Services. *Educational Psychology in Practice, 26,* 1-23.

Farrell, P T., Woods, K A., Squires, G., Rooney, S., Lewis, S., O'Connor, M. (2007). Educational Psychologists' contribution to the Every Child Matters agenda: the parents' view. *Educational Psychology in Practice, 23,* 343-361.

Feinberg, M.E., McHale, S., Crouter, A., & Cumsille, P. (2003). Sibling differentiation: sibling and parent relationship trajectories in adolescence. *Child Development, 74,* 1261-1274.

Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of children with chronic disabilities. *Canadian Journal of Psychiatry, 45,* 369–375.

Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. *Journal of the American Academy of Child and Adolescent Psychiatry, 35,* 1532–1541.

Flavell, J. H., Botkin, P. T., Fry, C. L., Jr., Wright, J. W., & Jarvis, P. E. (1968). *The development of role-taking and communication skills in children.* New York: Wiley.

Fleming, J. S., & Courtney, B. E. (1984). The dimensionality of self-esteem: II Hierarchical facet model for revised measurement scales. *Journal of Personality and Social Psychology, 46,* 404–421.

Floyd, F.J., Purcell, S.E., Richardson, S.S. Kupersmidt, J.B., & Abbeduto, L. (2009). Sibling relationship quality and social functioning of children and adolescents with intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 114,* 110-127.

Folkman, S., & Lazarus, R.S. (1986). The relationship between coping and emotion: Implications for theory and research. *Social Science Medicine, 26,* 309-317.

Fombonne, E. (2005a). The changing epidemiology of autism. *Journal of Applied Research in Intellectual Disabilities*, 18, 281–294.

Foster, C., Eiser, C., Oades, P., Sheldon, C., Tripp, J., Goldman, P., Rice, S., & Trott, J. (2001). Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: Patient, parent and sibling accounts. *Child: Care, Health and Development, 27*, 349-364.

Frank, N. (1996). Helping families support siblings. In P. J. Beckman (Ed.), *Strategies for working with families of young children with disabilities* (pp. 169-189). Baltimore: Paul Brookes.

Frith, U. (1989). *Autism: Explaining the Enigma.* Cambridge, MA: Basil Blackwell.

Furman, W., & Buhrmester, D. (1985). Children's perceptions of the qualities of sibling relationships. *Child Development, 56,* 448-461.

Gallagher, P. A., Powell, T. H., & Rhodes, C. A. (2006). Brothers and sisters: A special part of exceptional families (3rd ed.). Baltimore, MD: Paul H. Brookes Publishing.

Gallimore, R., Bernheimer, L.P., & Weisner, T. (1999). Family life is more than managing crisis: Broadening the agenda of research on families adapting to childhood disability. In Gallimore, R., Bernheimer, L.P., MacMillan, D.L., Speece, D.L. and Vaughn, S. (Eds.).*Developmental Perspectives on Children with High-Incidence Disabilities.* New Jersey & London: Lawrence Erlbaum Associates.

Gamble, W. C., & McHale, S. M. (1989). Coping with stress in sibling relationships: A comparison of children with disabled and non-disabled siblings. *Journal of Applied Developmental Psychology, 10,* 353–373.

Gass, K., Jenkins, J., & Dunn, J. (2007). Are sibling relationships protective? A longitudinal study. *Journal of Child Psychology and Psychiatry, 48,* 167-175.

Gibb, B. (1993). Providing support to sisters and brothers of children with disabilities. In G.H. Singer & L.E. Powers (Eds.). *Families, Disability, and Empowerment. Active Coping Skills and Strategies for Family Interventions.* Baltimore: Paul Brookes.

Glasberg, B. A. (2000). The development of siblings' understanding of autism spectrum disorders. Journal of Autism and Developmental Disorders, 30, 143–156.

Glidden, L.M. (1993). What we do not know about families with children who have developmental disabilities: questionnaire on resources and stress as a case study. *American Journal on Mental Retardation, 97,* 481-495.

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report, 8*, 597-607.

Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders, 23,* 147-163.

Grissom, M. O., & Borkowski, J. G. (2002). Self-efficacy in adolescents who have siblings with or without disabilities. *American Journal on Mental Retardation, 107,* 79–90.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18,* 59-82.

Guralnick, M.J. (2005). *The Developmental Systems Approach to Early Intervention.* Baltimore, Maryland: Paul H. Brookes.

Hannah, M. E., & Midlarsky, E. (2005). Helping by siblings of children with mental retardation. *American Journal on Mental Retardation, 110,* 87-99.

Hannah, M. E., & Midlarsky, E. (1999). Competence and adjustment of siblings of children with mental retardation. *American Journal on Mental Retardation, 104,* 22–37.

Harding, E., & Atkinson, C. (2009) How EPs record the voice of the child. *Educational and Child Psychology in Practice, 25,* 125-137.

Harris, J.R. (1995). Where is the child's environment? A group socialisation theory of development. *Psychological Review, 102,* 458-489.

Harris, J. R. (1995). Where is the child's environment? A group socialization theory of development. *Psychological Review*, 102, 458-489.

Harris, S. (1994). *Treatment of family problems in autism.* Plenum: NY

Harris, S.L., & Glasberg, B.E. (2003). *Siblings of children with autism: A guide for families.* Bethesda, MD: Woodbin House.

Hastings, R.P. (2007). Longitudinal relationships between sibling behavioural adjustment and behaviour problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders, 37,* 1485-1492.

Hastings, R.P. (2003a). Behavioural adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders, 33,* 99-104.

Hastings, R.P. (2003b). Behavioural adjustment of siblings of children with autism engaged in applied behaviour analysis early intervention programmes: The moderating role of social support. *Journal of Autism and Developmental Disorders, 33,* 141-150.

Hastings, R.P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behaviour problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111,* 48-61.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107,* 116-127.

Heller, K. W., Gallagher, P. A., & Fredrick, L. D. (1999). Parents' perceptions of siblings' interactions with their brothers and sisters who are deaf-blind. *JASH, 24,* 33–43.

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfield, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50,* 847-882.

Hodapp, R.M., Glidden, L.M., & Kaiser, A.P. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental Retardation, 43*, 334-338.

Hoddinott, P., & Pill, R. (1997). A review of recently published qualitative research in general practice: more methodological questions than answers? *Family Practice, 14,* 313-20.

Hoffman, R.M., John, H. A., & Borders, L.D. (2005). Personal definitions of masculinity and femininity as an aspect of gender self-concept. *Journal of Humanistic Counselling, Education and Development, 44,* 66-83.

Holloway, I., & Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative Research 3,* 345-357.

Holloway, I., & Wheeler, S. (2002) *Qualitative Research in Nursing.* Oxford: Blackwell.

Howe,N., & Recchia, H. (2006). Sibling relations and their impact on children's development. *Encyclopedia on Early Childhood Development.* 1-8. Available at: http://www.child-encyclopedia.com/documents/Howe-RecchiaANGxp.pdf. Accessed [19.04.2012].

Howell, A. N., Hauser-Cram, P., & Kersh, J. (2007). Setting the stage: Early family climate and feelings of loneliness in children with developmental disabilities. *American Journal on Mental Retardation, 112,* 18-30.

Howitt, D., & Cramer, D. (2008). (2nd Ed.). *Introduction to Research Methods in Psychology.* London: Prentice Hall.

Howlin, P. (1988). Living with impairment: The effects on children of having an autistic sibling. *Child: Care, Health, and Development, 14,* 395–408.

Hussey, J., & Hussey, R. (1997). *Business Research: A practical guide for undergraduate and postgraduate students.* Basingstoke: Macmillan.

Jordan, R. (2004) Meeting the Needs of Children with Autistic Spectrum Disorders in the Early Years. *Australian Journal of Early Childhood*, *29(3),* 1-7.

Ji-Yeon, K., McHale, S.M., Crouter, A.C., Wayne Osgood, D. (2007). Longitudinal linkages between sibling relationships and adjustment from middle childhood through adolescence. *Developmental Psychology, 43,* 960-973.

Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry, 43*, 225-232.

Kaminsky, L., & Dewey, D. (2001). Siblings relationships of children with autism. *Journal of Autism and Developmental Disorders, 31,* 399–410.

Kanner, L. 1943. Autistic disturbances of affective contact. *Nervous Child.* 2:217-250.

Kim, T., & Horn, E. (2009). Sibling-Implemented Intervention for Skill development With Children With Disabilities. *Topics in early Childhood Special Education, 30,* 80-90.

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism*, *13*, 317-336.

Knapp, M., Romeo, R., & Beecham, J. (2007). The economic consequences of autism in the UK. *Foundation for People with Learning Difficulties.*

Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: A comparison of autism and Down's syndrome. *Journal of Child Psychology and Psychiatry, 6,* 965–976.

Koegel, L. K., & LaZebnik, C. (2004). *Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's Life.* New York: Penguin Group.

Kovacs, M. & Beck, A.T. (1977). 'An empirical clinical approach towards a Definition of Childhood Clinical Depression', in J.G. Schulterbrandt & A. Raskin (eds) *Depression in Childhood: Diagnosis Treatment and Conceptual Models,* pp. 1-25. New York: Raven.

Kowal, A., & Kramer, L. (1997). Children's understanding of parental differential treatment. *Child Development, 68,* 113-126.

Kramer, L. & Bank, L. (2005) Sibling Relationship Contributions to Individual and Family Well-Being: introduction to the special issue, *Journal of Family Psychology*, 19(4), 483-485.

Krippendorff, K. (1980). *Content analysis: An introduction to its methodology*. London: Sage Publications, Ltd.

Kvale, S. (1996). *Interviews.* London: Sage.

Lardieri, L.A., Blacher, J., & Swanson, H. L. (2000). Sibling Relationships and Parent Stress in Families of Children with and without Learning Disabilities. *Learning Disability Quarterly, 23,* 105-116.

Lazarus, R.S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 55, 234-247.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Lobato, D. J., & Kao, B. T. (2002). Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *Society of Pediatric Psychology*, *27*, 711–716.

Lobato, D.J., Kao, B.T. & Plante, W. (2005) Latino Sibling Knowledge and Adjustment to Chronic Disability. *Journal of Family Psychology*, *19(4),* 625-632.

Lobato, D., Miller, C. T., Barbour, L., Hall, L. J., & Pezzullo, J. (1991). Preschool siblings of handicapped children: Interactions with mothers, brothers, and sisters. *Research in Developmental Disabilities, 12,* 387–399.

Lotter, V. (1966). Epidemiology of autistic conditions in young children: I. Prevalence. *Social Psychiatry,* 1, 124–137.

Lynch, D. J., Fay, L., Funk, J., & Nagel, R. (1993). Siblings of children with mental retardation: Family characteristics and adjustment. *Journal of Child and Family Studies, 2,* 87–96.

MacKay, T. (2006). The educational psychologist as community psychologist: Holistic child psychology across home, school and community. *Educational and Child Psychology, 23,* 7-15.

Macks, J.R., & Reeve, R.E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders, 37,* 1060-1067.

Mandleco, B., Olsen, S. F., Dyches, T., & Marshall, E. (2003). The relationship between family and sibling functioning in families raising a child with a disability. *Journal of Family Nursing, 9,* 365–396.

Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *British Journal of Developmental Disabilities, 52,* 19-28.

Mates, T.E. (1990). 'Siblings of autistic children: their adjustment at home and in school'. *Journal of Autism and Developmental Disorders, 20,* 545-553.

McCall, G., & Simmons, J. L. (Eds.). (1969). *Issues in participant observation*. Reading, MA: Addison-Wesley Press.

McCubbin, H.I., & Patterson, J. (1983). The family stress process: the double ABCX model of adjustment and adaptation. *Marriage and Family Review, 42,* 811-825.

McHale, S.M., Router, A.C., & Whiteman, S.D. (2003). The Family Contexts of Gender Development in Childhood and Adolescence. *Social Development, 12,* 125-148.

McHale, S.M., Kim, J. & Whiteman, S.D. (2006) Sibling Relationships in Childhood and Adolescence, in P. Noller & J.A. Feeney (Eds) *Close Relationships: functions, forms and processes*, 127-149. New York: Psychology Press.

McHale, S. M., & Pawletko, T. M. (1992). Differential treatment of siblings in two family contexts. *Child Development, 63,* 68–81.

McHale, S.M., Sloan, J., & Simeonsson, R.J. (1986). Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16,* 399-413.

McMahon, M. A., Noll, R. B., Michaud, L. J., & Johnson, J. C. (2001). Sibling adjustment to pediatric traumatic brain injury. *Journal of Head Trauma Rehabilitation, 16,* 587–594.

Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 22(1),* 83-100.

Meltzer, H. (2005). The prevalence of mental health and mental disorders in childhood and adolescence in Williams and Kerfoot (eds.) *Child and Adolescent Mental Health Services: strategy, planning, delivery and evaluation.* Oxford, UK: Oxford University Press.

Meyer, D. J., & Vadasy, P. F. (1994). *Sibshops: Workshops for siblings of children with special needs.* Baltimore: Paul Brookes.

Michaelis, C. T. (1980). *Home and school partnerships in exceptional children.* Rockville, MD: Aspen.

Miller, W. R., & Rollnick, S. (1991). Motivational interviewing: Preparing people for change. New York: Guilford Press.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: Sage Publications, Inc.

Minuchin, P. (1988). Relationships within the family: A systems perspective on development. In R. Hinde & J. Stevenson-Hinde (Eds.), *Relationships within families: Mutual influences* (pp.7-26). Oxford, UK: Clarendon.

Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy. *Child Development, 56,* 289-302.

Mitchell, D. (2004). *Stress, Coping and Appraisal in an HIV-Seropositive Rural Sample: A Test of the Goodness of Fit Hypothesis* (Unpublished master's thesis). Ohio University: Ohio.

Milvesky, A. (2005). Compensatory patterns of sibling support in emerging adulthood: Variations in loneliness, self-esteem, depression and life satisfaction. *Journal of Social and Personal Relationships*, *22*, 743-755.

Mishler, E. G. (2000). Validation in inquiry-guided research: The role of exemplars in narrative studies. In B. M. Brizuela, J. P. Stewart, R. G. Carrillo, & J. G. Berger (Eds.), *Acts of inquiry in qualitative research* (pp. 119-146). Cambridge, MA: Harvard Educational Review.

Moes, D. R., & Frea, W. D. (2002). Contextualized behavioral support in early intervention for children with autism and their families. *Journal of Autism and Developmental Disorders, 32*(6), 519–533.

Moore, T.G. (2008). *Early childhood intervention: Core knowledge and skills. CCCH Working Paper 3.* Parkville, Victoria: Centre for Community Child Health.

Morris, J. (1998). *Still Missing? Vol.2: disabled children and the Children Act.* London: Who Cares? Trust.

Moyson, T., & Roeyers, H. (2001). 'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives. *Journal of Intellectual Disability Research, 56,* 87–101.

National Institute of Health (NIH). (2009). *Strategic plan for autism related disorders*. Retrieved July 20, 2009, from http:// www.iacc.hhs.gov/reports/2009/iacc-strategic-plan-for-autism.

Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. *British Journal of Special Education, 31*, 199-206. Neuendorf, K. A. (2002). *The content analysis guidebook*. Thousand Oaks, CA: Sage Publications, Inc.

Newman, J. (1994). Conflict and friendship in sibling relationships: A review. *Child Study Journal, 24,* 119-148.

Newschaffer, C.J., Croen, L.A., Daniels, J., Giarelli, E., Grether, J.K., Levy, S.E.,... & Windham, G.C. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health. 28*, 235-258.

Newschaffer, C.J., Fallin, D., & Lee, N. (2007). Heritable and nonheritable risk factors for autism spectrum disorders. *Epidemiological Reviews, 24,* 137-153.

Nixon, C. L., & Cummings, E. M. (1999). Sibling disability and children's reactivity to conflicts involving family members. *Journal of Family Psychology, 13,* 274–285.

O'Brien, K., Slaughter, V., Peterson, C.C. (2011). Sibling influences on theory of mind development for children with ASD. *Journal of Child Psychology and Psychiatry, 52,* 713–719.

Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. *Qualitative Social Research, 7(4).*

Oppenheim, A.N. (1992). *Questionnaire Design, Interviewing and Attitude Measurement.* London: Pinter Publishers.

Opperman, S., & Alant, E. (2003). The coping responses of the adolescent of children with severe disabilities. *Disability and Rehabilitation, 25,* 441-454.

Orsmond, G.I. & Seltzer, M.M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities, 13,* 313-320.

Patton, M. Q. (2002). *Qualitative evaluation and research methods.* Thousand Oaks, CA: Sage Publications, Inc.

Patton, M. Q. (2002). *Qualitative evaluation and research methods.* Thousand Oaks, CA: Sage Publications, Inc.

Patton, M.Q. (1980). *Qualitative evaluation methods.* Newbury Park, CA: Sage

Petalas, M.A., Hastings, R.P., Nash, S., Dowey, A., & Reilly, D. (2009). "I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, 56,* 381-399.

Petalas, M.A., Hastings, R.P., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism, 13,* 471-483.

Piaget, J. (1929). The child's conception of the world. London: Routledge & Kegan Paul.

Pickles, A., Starr, E., Kazak, S., Bolton, P., Papanikolaou, K., Bailey, A., et al. (2000). Variable expression of the autism broader phenotype: Findings from extended pedigrees. *Journal of Child Psychology and Psychiatry, 41,* 491–502.

Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R.S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry, 45,* 855-865.

Piven, J. (1999). Genetic liability for autism: The behavioral expression in relatives. *International Review of Psychiatry, 11,* 299–308.

Piven, J., Palmer, P., Jacobi, D., Childress, D., & Arndt, S. (1997). Broader autism phenotype: Evidence from a family history study of multiple-incidence autism families. *American Journal of Psychiatry, 154,* 185– 190.

Popay, J., Williams, G., & Rogers, A. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research, 8,* 341-51.

Pope, C., Ziebland, S., & Mays, N. (2000). Analysing qualitative data. *British Medical Journal 320*, 114-116.

Powell, T. H., & Gallagher, P. A. (1993). *Brothers and sisters: A special part of exceptional families.* Baltimore: Paul Brookes.

Riffe, D., Lacy, S., & Fico, F. (1998). *Analyzing media messages: Using quantitative content analysis in research*. Mahwah, NJ: Lawrence Erlbaum.

Rivers, J.W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: marital stress and support coping. *Journal of Autism and Developmental Disorders, 33,* 383–394.

Robson, C. (1993) *Real World Research. A Resource for Social Scientists and Practitioner-Researchers*. Oxford: Basil Blackwell.

Rodrigue, J.R., Geffken, G.R., & Morgan, S.B. (1993). Perceived competence and behavioural adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders, 23,* 655-674.

Roeyers, H., & Mycke, K. (1995). Siblings of children with autism, with mental retardation and with normal development. *Child: Care, Health and Development, 21,* 305–319.

Ross, P., & Cuskelly. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autism spectrum disorder. *Journal of Intellectual and Developmental Disabilities, 31* (2), 77-86.

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies, 10,* 65-84.

Rowitz, L. (1993). Lifetime research on siblings of persons with mental retardation. In Z. Stoneman & P. W. Berman (Eds.), *The effects of mental retardation, disability and illness on sibling relationships: Research issues and challenges* (pp. 321–332). Baltimore: Brookes.

Roulston, K. 2001: Data analysis and 'theorizing as ideology'. *Qualitative Research, 1,* 279-302.

Rutter, M. (2000). Genetic studies of autism: From the 1970s into the millennium. *Journal of Abnormal Child Psychology, 28,* 3–14.

Rutter, M. (1991). Services for children with emotional disorders: Needs, accomplishments and future developments. *Young Minds Newsletter, 9,* 1-5.

Rutter, M. (1978). Diagnosis and definition. In M. Rutter & E. Schopler (Eds) *Autism: A reappraisal of concepts and treatment.* New York: Plenum Press.
Samalin, N. (1996). *Loving each one best: A caring and practical approach to raising siblings.* New York: Bantam.

Sameroff, A. (1994). Developmental systems and family functioning. In R.D. Parke & S.G. Kellam (Eds.), *Exploring family relationships with other social contexts. Family research consortium Advances in family research* (pp.199-214). Hillsdale, NJ: Earlbaum.

Sanders, R. (2004) *Sibling Relationships: theory and issues for practice*. Basingstoke: Palgrave Macmillan.

Santrock J.W., & Yussen, S.R. (1992). *Child development: An Introduction (5th ed).* Dubuque, IA: Wm C Brown Publishers.

Sarbin, T. R. (1954). Role theory. In G. Lindzey (Ed.), *Handbook of social psychology* (pp. 223–258). Reading, MA: Addison-Wesley.

Schaffir, W. B., & Stebbins, R. (1991). *Experiencing fieldwork*. Newbury Park, CA: Sage Publications.

Scharf, M., Schulman, S., & Avigad-Spitz, L. (2005). Sibling relationships in emerging adulthood and adolescence. *Journal of Adolescent Research, 20* (1), 64-90.

Seale, C. (1999). Quality in qualitative research. *Qualitative Inquiry, 5*(4), 465-478.
Seale, C., & Silverman, D. (1997). Ensuring rigour in qualitative research. *European Journal of Public Health, 7,* 379-84.

Seligman, M., & Darling, R. B. (1989). *Ordinary families, special children: A systems approach to childhood disability.* New York: Guilford Press.

Seltzer, M.M., Abbeduto, L., Krauss, M.W., Greenberg, J., & Swe, A. (2004). Comparison groups in autism family research: Down syndrome, fragile X syndrome, and schizophrenia. *Journal of Autism and Developmental Disorders, 34*, 41-48.

Seltzer, M.M., Greenberg, J.S., Orsmond, G.I. & Lounds, J. (2005) Life Course Studies of Siblings of Individuals with Developmental Disabilities, *Mental Retardation*, *43(5),* 354-359.

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Paediatric Psychology, 27,* 699-710.

Shavelson, R. J., & Bolus, R. (1982). Self-concept: The interplay of theory and methods. *Journal of Educational Psychology, 74,* 3-17.

Singhi, P., Malhi, P., & Dwarka, P. (2002). Psychological adjustment of siblings of children with disabilities. *Journal of Personality and Clinical Studies, 18,* 9–18.

Smith, A.L. (2010).Examining the Role of Communication on Sibling Relationship Quality and Interaction for Sibling Pairs with and without a Developmental Disability. *Psychology Dissertations.* Paper 81. ttp://digitalachive.gsu.edu/psych_diss/81.

Smith, L.O., & Elder, J.H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing, 23*, 189-195.

Snyder, C. R. (1994). *The psychology of hope. You can get there from here*.
New York: Free Press.

Sparrow, S.S., Balla, D.A., & Cicchette, D.V. (1984). *Vineland Adaptive Behaviour Scales.* Circle Pines, MN: American Guidance Service.

Stalker, K., & Connors, C. (2004). Children's perceptions of their disabled siblings: she's different but it's normal for us. *Children and Society, 18,* 218-230.

Stenbacka, C. (2001). Qualitative research requires quality concepts of its own. *Management Decision, 39*(7), 551-555.

Stiles, W.B. (1993). Quality control in qualitative research. *Clinical Psychology Review, 13,* 593-618.

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation, 43,* 339-350.

Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. Mental Retardation and Developmental Disabilities. *Research Reviews, 7,* 134-142.

Stoneman, Z. (1998). Research on siblings of children with mental retardation: Contributions of developmental theory and etiology. In J. A. Burack, R. M. Hodapp & E. Zigler (Eds.) *Handbook of Mental Retardation and Development.* (pp. 669-692). Cambridge, UK: Cambridge University Press.

Stoneman, Z. (1993). Common themes and divergent paths. In Z. Stoneman & P.W. Berman (Eds.). *The effects of mental retardation, disability and illness on sibling relationships* (pp.355-365). Baltimore: Brookes.

Stoneman, Z., & Brody, G. H. (1993). Sibling relations in the family context. In Z. Stoneman & P. W. Berman (Eds.), The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges. (pp. 3-30). Baltimore, MD, England: Paul H. Brookes Publishing.

Stoneman, Z., & Brody, G.H. (1984). Research with families of severely handicapped children: Theoretical and methodological considerations. In J. Blatcher (Ed.), *Severely handicapped young children and their families: Research in review* (pp.179-214). San Diego, CA: Academic Press.

Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M., & Malone, D. M. (1991). Ascribed role relations between children with mental retardation and their younger siblings. *American Journal on Mental Retardation, 95,* 537–550.

Stores, R., Stores, G., Fellows, B., & Buckley, S. (1998). Daytime behaviour problems and maternal stress in children with Down's syndrome, their siblings, and non-intellectually disabled and other intellectually disabled peers. *Journal of Intellectual Disability Research, 42,* 228–237.

Strain, P.S., & Danko, C. (1995). Caregivers' encouragement of positive interaction between preschoolers' with autism and their siblings. *Journal of Emotional and Behavioral Disorders, 3*, 12-12.

Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities, 37,* 410–420.

Taylor, S. E. (2006). *Health psychology.* Boston: McGraw-Hill Higher Education

Tomeny, T.S., Barry, T.D., & Bader, S.H. (2012). Are typically-developing siblings of children with an autism spectrum disorder at risk for behavioral, emotional, and social maladjustment? *Research in Autism Spectrum Disorders*, *6, 508-518.*

Toth, K., Dawson, G., Meltzoff, A.N., Greenson, J., & Fein, D. (2007). Early social, imitation, play, and language abilities of young non-autistic siblings of children with autism. *Journal of Autism and Developmental Disorders, 37*, 145-157.

Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse, 19*, 75-87.

Turnbull, A.P. and Turnbull, R. (2003). Begin with the end in mind: Individuals with disabilities and their families living life to the fullest. In B. F. Williams. (Ed.) *Directions in Early Intervention and Assessment.* Spokane, Washington: Spokane Guilds' School and Neuromuscular Center.

Turnbull, A. P. & Turnbull, H. R. (2001). *Families, professionals and exceptionally: collaborating for empowerment (4th Edition).* New Jersey: Prentice Hall, Inc.

United Nations (1989) *Convention on the Rights of the Child (UNCRC).* Geneva.

VanRiper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing, 6,* 267–286.

Verte, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self concept in siblings of children with autism. *Child: Care, Health & Development, 29,* 193-205.

Vitaliano, P. P., Maiuro, R. D., Russo, J., & Becker, J. (1987). Raw versus relative scores in the assessment of coping strategies. *Journal of Behavioral Medicine, 10*, 1-18.

Wade, J.C. (1998). Male reference group identity dependence: a theory of male identity. *The Counselling Psychologist, 26,*349-383.

Watt, D. (2007). On becoming a qualitative researcher: The value of reflexivity. *The Qualitative Report, 12,* 82-101.

Weiss, M.J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism, 6,* 115-130.

Weiten, W. & Lloyd, M.A. (2008). *Psychology Applied to Modern Life.* Wadsworth: Cengage Learning.

Wikler, L. (1986). Chronic stresses of families of mentally retarded children. *Family Relations, 30,* 281-288.

Wing, L. & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders,* 9, 11-29.

Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews, 8,* 151-161.

Wing, L., Yeates, S. R., Brierly, L. M., & Gould, J. (1976). The prevalence of early childhood autism: Comparison of administrative and epidemiological studies. *Psychological Medicine*, 6, 89–100.

Winter, G. (2000). A comparative discussion of the notion of validity in qualitative and quantitative research. *The Qualitative Report, 4,* 3-4. Retrieved 11.04.2012 from http://www.nova.edu/ssss/QR/QR4-3/winter.html.

Wolf, L., Fisman, S., Ellison, D., & Freeman, T. (1998). Effect of sibling perception of differential treatment in sibling dyads with one disabled child. *Journal of the American Academy of Child and Adolescent Psychiatry, 37,* 1317-1325.

Yirmiya, N., Gamliel, I., Shaked, M., & Sigman, M. (2007). Cognitive and verbal abilities of 24- to 36-month-old siblings of children with autism. *Journal of Autism and Developmental Disorders, 37*(2), 218–229.

Appendix One: Pre-pilot semi-structured interview

1. Tell me a bit about yourself?

2. Who is in your family?

3. What are your hobbies and interests?

Perceptions

1. What do you know about autism?

2. Describe (=insert name of sibling with autism=)to me.

3. Tell me what it is like to be (=insert name of sibling with autism=)'s brother or sister?

4. Describe what your relationship is like with (=insert name of sibling with autism=).How do you get on?

5. Are there good things about being (=insert name of sibling with autism=)'s brother/sister? What are the good things that you do with (=insert name of sibling with autism=)?

6. Are there bad things about being (=insert name of sibling with autism=)'s brother/sister? How does this make you feel?

7. Describe what is it like to live with (=insert name of sibling with autism=)? (Discuss in the context of a typical day).

8. How does being a brother/sister of (=insert name of sibling with autism=) affect your life?

9. What advice would you give to other children/young people who have a brother/sister with autism?

10. How do you feel other people think about (=insert name of sibling with autism=)?

11. How would things be different if (=insert name of sibling with autism=) did not have autism?

12. In what ways do you think having a brother or sister with autism will affect your future? What do you think and feel about this?

13. How do your parents/carers treat you differently compared to (=insert name of sibling with autism=)?

Coping Responses

1. Can you tell me some more about how (=insert name of sibling with autism=)'s behaviour affects you? What do you usually do when this happens? Can you tell me some more about how this makes you feel?

2. Does (=insert name of sibling with autism=)'s autism affect how you feel sometimes? Can you tell me some more about these feelings?

3. Think of a stressful time between you and (=insert name of sibling with autism=) in the past month. How did you cope or what did you do afterwards? How you usually deal with things? [Consider the following strategies: distraction; social withdrawal; wishful thinking; blaming others; problem solving; emotional regulation; cognitive restructuring; social support; resignation].

4. When things are hard do you feel you are able to get support? If so where does this support come from?

5. In what ways could there be more help and support for you? How would this help you cope with having a brother/sister with autism?

6. What advice could you give to other children and young people about ways to cope with having a brother/sister with autism? What do you think are the best ways to cope?

7. Can you tell me about some ways that you have tried to cope when you have had a difficult time with (=insert name of sibling with autism=)?

8. Can you tell me how often and when you use these ways to cope?

Appendix Two: Post-pilot semi-structured interview

1. Tell me a bit about yourself?

2. Who is in your family?

3. What are your hobbies and interests?

4. What do you know about autism?

5. Describe (=insert name of sibling with autism=) to me.

6. What it is like to be (insert name of sibling with autism)'s brother/sister?

7. Do you get on with one another?

8. What is it like to live with (insert name of sibling with autism)?

9. Does having a brother with autism affect your life?

10. What advice would you give to other children/young people who have a brother/sister with autism?

11. What do other people think of (insert name of sibling with autism)?

12. How would things be different if (=insert name of sibling with autism=) did not have autism?

13. Does (=insert name of sibling with autism=) affect you?

14. How do you cope?

15. Are you able to get help and support?

16. In what ways could be more support or help for you or other siblings of children with autism?

17. Do you think (=insert name of sibling with autism=) will affect your future?

Appendix Three: Letter to gatekeepers

XXXXXXX School/Provision
XXXXXXX XXXXX
XXXXXXX
XXX XXX

Dear [Title] [Sir Name]

Re: Siblings of children and young people with autism. An exploration of typical siblings' constructions, perceptions and coping responses.

I am a Trainee Educational Psychologist (TEP) on the Doctorate in Educational Psychology professional training programme at Cardiff University. I am interested in conducting some research in your school and as part of my doctoral thesis I intend to explore the experiences of siblings of children and young people with autism.

In order to participate in the research sibling participants will be required to complete a short face to face interview with the researcher that will last a maximum duration of forty five minutes. The questions in the interview aim to explore typical siblings' constructions, perceptions and coping responses when growing up with a brother with autism.
This research intends to inform support services for children and young people in community and education settings.

The inclusion criteria for the research are as follows.

- Male/female siblings.
- Aged 8-20 years.
- Siblings must have a brother with a formal diagnosis of autism (and no other additional needs/disabilities).
- Siblings must be typically developing and have no additional needs/disabilities.

If you feel that you have children/young people in your setting who meet the inclusion criteria and may wish to engage with this research then I will contact you on [insert date] to discuss this further. In order to conduct this research it is hoped that you will be in a position to provide the details of parents of children who meet the inclusion criteria. If you do not wish to pass personal information to the researcher, then the researcher will provide the necessary resources (i.e., letters for parents, stamped envelopes, stamped addressed-envelopes etc.) for you to pass directly to families. If you do not wish to engage with this

research please can you complete the attached form and return it in the stamped addressed envelope provided. Parents will be contacted in writing to invite children/young people to participate in the research. All data and personal information will be stored confidentially and securely and will be destroyed at the end of the research. All participants are free to withdraw from this research at any point without reason. Ethical approval has been provided by the School of Psychology's Research Ethics Committee (SREC) at Cardiff University. This research will be supervised by Mr. John Gameson (Professional Director, Doctorate in Educational Psychology Professional Training Programme). The researcher (Sara Roberts) has an enhanced CRB disclosure.

Many thanks in advance for your consideration of this project.

Yours sincerely,

Sara Roberts
Trainee Educational Psychologist (TEP)

Sara Roberts	**Mr. John Gameson**
Trainee Educational Psychologist	Professional Director
School of Psychology	DEdPsy Professional Training Programme
Cardiff University	School of Psychology
Tower Building	Cardiff University
Park Place	Tower Building
Cardiff. CF10 3AT.	Park Place
	Cardiff. CF10 3AT
Tel: 02920 875393	Tel: 02920 875474
Email: robertssl4@cardiff.ac.uk	Email: GamesonJ@Cardiff.ac.uk
In case of complaint, please contact the Psychology Ethics Committee Secretary:	
Psychology Ethics Committee Secretary	Email: psychethics@cf.ac.uk
Cardiff University	Phone: +44 (0)29 20875007
Tower Building	Fax: +44 (0)29 20874858
Park Place	
Cardiff	
CF10 3AT	

If you wish to withdraw from this research please complete this form and return it in the stamped addressed envelope provided by [insert date]:

I _____ (name)

of _____ (school name)

wish to be withdrawn from the research on *"Siblings of children and young people with autism spectrum disorder (ASD). An exploration of siblings' perceptions and coping responses"*.

Appendix four: Consent form for gatekeepers

School of Psychology, Cardiff University

Siblings of children and young people with autism. An exploration of typical siblings' constructions, perceptions and coping responses.

This research is being conducted by Sara Roberts a Trainee Educational Psychologist on the Doctorate in Educational Psychology Professional Training Programme at Cardiff University, as part of her doctoral thesis research. Please can you read the statements below and sign your name at the bottom of the page if you wish to participate in this research:

I understand that my participation in this research will require that I provide contact information for families who meet the inclusion criteria for this research. I understand that the information I provide will be stored confidentially and securely (e.g., in a lockable storage unit) and that this information will not be passed to any third party. I understand that the researcher (Sara Roberts) will use the information I provide to contact parents of siblings to invite them to participate in this research.

Alternatively I understand that I will participate in this research by contacting families directly and passing them the relevant resources provided by the researcher (Sara Roberts).

I understand that I am free to withdraw from this research at any point without giving a reason. I understand that I am free to ask any questions at any time. I am free to discuss my concerns with the researcher (Sara Roberts) or submit any queries or complaints to Psychology Ethics Committee Secretary.

The project is being supervised by Mr. John Gameson, Professional Director, Doctorate in Educational Psychology Professional Training Programme, School of Psychology, Cardiff University.

I, _____(NAME) consent to participate in the study conducted by Sara Roberts, School of Psychology, Cardiff University with the supervision of Mr. John Gameson.

Signed:
Date:

Sara Roberts Trainee Educational Psychologist School of Psychology Cardiff University Tower Building Park Place Cardiff. CF10 3AT. Tel: 02920 875393 Email: robertssl4@cardiff.ac.uk	**Mr. John Gameson** Professional Director DEdPsy Professional Training Programme School of Psychology Cardiff University Tower Building Park Place Cardiff. CF10 3AT Tel: 02920 875474 Email: GamesonJ@Cardiff.ac.uk

In case of complaint, please contact the Psychology Ethics Committee Secretary:

Psychology Ethics Committee Secretary Cardiff University Tower Building Park Place Cardiff CF10 3AT	Email: psychethics@cf.ac.uk Phone: +44 (0)29 20875007 Fax: +44 (0)29 20874858

Appendix Five: Research packs and information for parents (Letter to parents and consent form).

XXXXXXX
XXXXXXX XXXXX
XXXXXXX
XXX XXX

Dear [Title] [Sir Name]

Re: Siblings of children and young people with autism. An exploration of typical siblings' constructions, perceptions and coping responses.

I am a Trainee Educational Psychologist (TEP) on the Doctorate in Educational Psychology professional training programme at Cardiff University. I am interested in conducting some research as part of my doctoral thesis and I intend to explore the constructions, perceptions and coping responses of typical siblings of children with autism.

In order to participate in the research sibling participants will be required to complete a face to face interview with the researcher that will last a maximum duration of forty five minutes.

This research intends to inform support services for children and young people in community and education settings.

The inclusion criteria for the research are as follows.

- Male/female siblings.
- Aged 8-20 years.
- Siblings must have a brother with a formal diagnosis of autism (and no other additional learning needs/disabilities).
- Siblings must be typically developing and have no additional needs/disabilities.

If you feel that your child may wish to engage with this research then I will contact you on [insert date] to discuss this further. If you do not wish to engage with this research please can you complete the attached form and return it in the stamped addressed envelope provided.

235

Participants will be free to withdraw from the research up until the point at which the data is transcribed and becomes anonymous two weeks after the interviews take place. Data will be coded at this point to facilitate anonymity, and will not be linked or traced to any participant. Ethical approval for this research has been provided by the School of Psychology's Research Ethics Committee (SREC) at Cardiff University. This research will be supervised by Mr. John Gameson (Professional Director, Doctorate in Educational Psychology Professional Training Programme). The researcher (Sara Roberts) has an enhanced CRB disclosure. Many thanks in advance for your consideration of this project.

Yours sincerely,

Sara Roberts
Trainee Educational Psychologist (TEP)

Sara Roberts	**Mr. John Gameson**
Trainee Educational Psychologist	Professional Director
School of Psychology	DEdPsy Professional Training Programme
Cardiff University	School of Psychology
Tower Building	Cardiff University
Park Place	Tower Building
Cardiff. CF10 3AT.	Park Place
	Cardiff. CF10 3AT
Tel: 02920 875393	Tel: 02920 875474
Email: robertssl4@cardiff.ac.uk	Email: GamesonJ@Cardiff.ac.uk

In case of complaint, please contact the Psychology Ethics Committee Secretary:	
Psychology Ethics Committee Secretary	Email: psychethics@cf.ac.uk
Cardiff University	Phone: +44 (0)29 20875007
Tower Building	Fax: +44 (0)29 20874858
Park Place	
Cardiff	
CF10 3AT	

- -

If you wish to withdraw from this research please detach and complete this form and return it in the stamped addressed envelope provided by [insert date]:

I _____ (name)
Wish to be withdrawn from the research on *"Siblings' of children and young people with autism spectrum disorder (ASD). An exploration of siblings' perceptions and coping responses".*

School of Psychology, Cardiff University

Siblings of children and young people with autism.
An exploration of typical siblings' constructions, perceptions and coping responses.

This research is being conducted by Sara Roberts a Trainee Educational Psychologist on the Doctorate in Educational Psychology Professional Training Programme at Cardiff University, as part of her doctoral thesis research. Please can you read the statements below and sign your name at the bottom of the page is you wish to participate in this research:

I understand that my participation in this project will require that I consent to allow the researcher (Sara Roberts) to contact my child. I understand that my child will be required to participate in a face to face interview with the researcher (Sara Roberts) that will last no longer than thirty minutes in duration. I understand the interview questions will explore my child's constructions, perceptions and coping responses.

I understand that the information my child provides will be stored confidentially and securely (e.g., in a lockable storage unit) and that this information will not be passed to any third party. I understand that my child is free to withdraw from this research at any point, up until the time at which the interview data is transcribed and subsequently anonymised. The data will be anonymised two weeks after the interview takes place.

I understand that I am free to ask any questions at any time. I am free to discuss my concerns with the researcher (Sara Roberts) or submit any queries or complaints to Psychology Ethics Committee Secretary. The project is being supervised by Mr. John Gameson, Professional Director, Doctorate in Educational Psychology Professional Training Programme, School of Psychology, Cardiff University.

I, _____(NAME) consent to participate in the study conducted by Sara Roberts, School of Psychology, Cardiff University with the supervision of Mr. John Gameson.

Signed:

Date:

Sara Roberts Trainee Educational Psychologist School of Psychology Cardiff University Tower Building Park Place Cardiff. CF10 3AT. Tel: 02920 875393 Email: robertssl4@cardiff.ac.uk	**Mr. John Gameson** Professional Director DEdPsy Professional Training Programme School of Psychology Cardiff University Tower Building Park Place Cardiff. CF10 3AT Tel: 02920 875474 Email: GamesonJ@Cardiff.ac.uk

In case of complaint, please contact the Psychology Ethics Committee Secretary:

Psychology Ethics Committee Secretary Cardiff University Tower Building Park Place Cardiff CF10 3AT	Email: psychethics@cf.ac.uk Phone: +44 (0)29 20875007 Fax: +44 (0)29 20874858

Appendix Six: Debriefing form for parents

School of Psychology, Cardiff University

Siblings of children and young people with autism.
An exploration of typical siblings' constructions, perceptions and coping responses.

Thank you for your participation in this research project. The purpose of this research was to explore the constructions, perceptions and coping responses of typical siblings of children and young people with autism. This research aims to inform the development of support services in community and educational settings.

The information you have provided will be stored confidentially and securely (e.g., in a lockable storage unit) and this information will not be passed to any third party. The researcher (Sara Roberts) will use the information you have provided to contact parents of siblings to invite them to participate in this research.
Alternatively you will have been provided with the resources by the researcher (Sara Roberts), to contact families and invite them to participate.

The information you have provided can be withdrawn at any point without giving a reason. If you require any further information please contact the researcher (Sara Roberts). Any queries or complaints should be submitted to the Psychology Ethics Committee Secretary. The project is being supervised by Mr. John Gameson, Professional Director, Doctorate in Educational Psychology Professional Training Programme, School of Psychology, Cardiff University.

Thank you for participating in this research.

Appendix Seven: Consent form for participants

School of Psychology, Cardiff University

Siblings of children and young people with autism.
An exploration of typical siblings' constructions, perceptions and coping responses.

This research is being conducted by Sara Roberts a Trainee Educational Psychologist on the Doctorate in Educational Psychology Professional Training Programme at Cardiff University, as part of her doctoral thesis research. Please can you read the following statements and sign your name at the bottom of the page if you wish to participate in this research:

I understand that my participation in this project will require that I participate in a face to face interview with the researcher (Sara Roberts) that will last no longer than thirty minutes in duration. I understand that the open-ended interview will explore my feelings about having a brother with autism and how I cope with this.

I understand that the information I provide will be stored confidentially and securely (e.g., in a lockable storage unit) and that this information will not be passed to any third party. I understand that I am free to withdraw from this research at any point, up until the time at which the interview data is transcribed and subsequently anonymised. The data will be transcribed and anonymised two weeks after the interview takes place.

I understand that I am free to ask any questions at any time. I am free to discuss my concerns with the researcher (Sara Roberts), or submit any queries or complaints to Psychology Ethics Committee Secretary. The project is being supervised by Mr. John Gameson, Professional Director, Doctorate in Educational Psychology Professional Training Programme, School of Psychology, Cardiff University.

I, _____(NAME) consent to participate in the study conducted by Sara Roberts, School of Psychology, Cardiff University with the supervision of Mr. John Gameson.

Signed:

Date:

Sara Roberts Trainee Educational Psychologist School of Psychology Cardiff University Tower Building Park Place Cardiff. CF10 3AT. Tel: 02920 875393 Email: robertssl4@cardiff.ac.uk	**Mr. John Gameson** Professional Director DEdPsy Professional Training Programme School of Psychology Cardiff University Tower Building Park Place Cardiff. CF10 3AT Tel: 02920 875474 Email: GamesonJ@Cardiff.ac.uk

In case of complaint, please contact the Psychology Ethics Committee Secretary:

Psychology Ethics Committee Secretary Cardiff University Tower Building Park Place Cardiff CF10 3AT	Email: psychethics@cf.ac.uk Phone: +44 (0)29 20875007 Fax: +44 (0)29 20874858

Appendix Eight: Debriefing form for participants

School of Psychology, Cardiff University

Siblings of children and young people with autism.
An exploration of typical siblings' constructions, perceptions and coping responses.

Thank you for participating in this research project. The purpose of this research was to explore how you feel about having a brother with autism and how you cope. This research may help to develop support services for children and young people with a brother/sister with autism.

The information you have provided will be stored confidentially and securely (e.g., in a lockable storage unit) and this information will not be passed to anyone else. You are able to withdraw your data up until the point at which it is transcribed and becomes anonymous. All data will be transcribed and subsequently anonymised approximately two weeks after the interview takes place.

If you require any further information please contact the researcher (Sara Roberts). Please submit any queries or complaints to Psychology Ethics Committee Secretary. The project is being supervised by Mr. John Gameson, Professional Director, Doctorate in Educational Psychology Professional Training Programme, School of Psychology, Cardiff University.

Thank you for participating in this research.

Sara Roberts	**Mr. John Gameson**
Trainee Educational Psychologist	Professional Director
School of Psychology	DEdPsy Professional Training Programme
Cardiff University	School of Psychology
Tower Building	Cardiff University
Park Place	Tower Building
Cardiff. CF10 3AT.	Park Place
	Cardiff. CF10 3AT
Tel: 02920 875393	Tel: 02920 875474
Email: robertssl4@cardiff.ac.uk	Email: GamesonJ@Cardiff.ac.uk
In case of complaint, please contact the Psychology Ethics Committee Secretary:	

Psychology Ethics Committee Secretary	Email: psychethics@cf.ac.uk
Cardiff University	Phone: +44 (0)29 20875007
Tower Building	Fax: +44 (0)29 20874858
Park Place	
Cardiff	
CF10 3AT	

Appendix Nine: Example transcript

Participant ID:	**S08.**
Interview Name:	**Siblings of children and young people with autism.**
Site:	**Home address of participant.**
Date of Interview:	**13.07.2011.**
Interviewer ID:	**ISR01.**
Transcriber:	**Sara Roberts.**

ISR01##
OK, before we begin the interview itself, I need to make sure that you have read, understood and signed the consent form. I also need to check that you understand that your participation in this research is voluntary. You can choose not to answer any of the questions, and we can stop the interview at any time.

##S08##
Yes.

ISR01##
Do you have questions before we proceed?

##S08##
No.

ISR01##
Tell me a bit about yourself?

##S08##
Oh, ok (long pause), well my name is (=name of typical sibling=), but most people call me (=nick name of typical sibling=). I am really into cooking and want to be a top chef. I am starting catering college soon.

ISR01##
Wow, are you looking forward to it?

##S08##
Yes, I can't wait. I dropped out of college last year as it was boring, so I am looking forward to trying something new, and something I care about. I've been bored at home for a bit now (laughs).

ISR01##
(Laughs) I understand. So, who is in your family?

##S08##
My brother (=name of sibling with autism=), he is fourteen. Then (pause) just mum and dad. Dad works long hours, and he is away a lot.

243

ISR01##
I see. What are your hobbies and interests?

##S08##
Well cooking (short sharp laugh). I like video games and music and stuff. I've got decks and I like to mix. I am really into house and dub step.

ISR01##
I understand moving house can be difficult, especially if you have moved away from your friends.

##S08##
Yeh, it blows (laughs).

ISR01##
So, what do you know about autism?

##S08##
To be honest I am still quite unsure about it.

ISR01##
Ok (long pause).

##S08##
All I know is that it affects the way that my brother (=insert name of sibling with autism=) is able to see things. He sees things in a different light. (CODE A2).

ISR01##
What do you mean?

##S08##
(Long pause) mmm well say you told him "it's raining cats and dogs" he would look outside and he takes things literally and as they are. So you have to be really careful about how you word things. He might think about things completely differently to how I see things. He can be very opinionated. (CODE A2).

ISR01##
Describe (insert name of sibling with autism) to me.

##S08##
Sporty (pause). He likes doing things. He is quite active I guess. He can be quite practical too. (CODE B2).

ISR01##
I see. What it is like to be (insert name of sibling with autism)'s brother?

##S08##
Difficult.

ISR01##
Difficult?

##S08##
Well because of the fact that his autism is quite bad. You have to tip-toe around him, especially in the morning because that is when he is at his worst. Especially during school time. (CODE D2).

ISR01##
What are the main issues in the mornings?

##S08##

He doesn't like school. His school is too big for him and he has lots of problems. Monday mornings are always the worst as it is the first day back after the weekend and it's very difficult. He is really anxious. I just try not to trigger him off. I mean even the word 'good morning' could flip a switch and spark him off. **(CODE D2).** I just keep my head down and keep out of the way. **(CODE E3).**

ISR01##

I see. Do you get on with one another?

##S08##

I wouldn't say we were close (long pause) more that we are just living in the same house really. **(CODE B4).** We get on with each other, but then there's getting on and there's getting on. **(CODE B4).** He likes being around me and he wants to do something good for you. Like he will put himself out of his way for you (long pause) sometimes. Like depending on how he is feeling. **(CODE D4).**

ISR01##

What is it like to live with (insert name of sibling with autism)?

##S08##

It can be hard, because normally I am the first one attacks first. If he does flare up. **(CODE D2).**

ISR01##

That sounds hard. What do you mean by flare up?

##S08##

Well that's just the way I put it (pause) it's just a way of saying how he goes completely out of control. He is not happy and is just completely angry. He wants to literally destroy the place. It will be like a small thing (pause) maybe an argument or a little wind up or something. **(CODE D2).** He is better now because of the medication and stuff but it still obviously happens every now and then. **(CODE D4).** Like yesterday it happened. Like he will flare up and then he tries to wind me up (pause), then I start to get wound up and everything flares up and then he will go and be really hands on. He can go for hours. **(CODE D2).**

ISR01##

What do you mean by hands on?

##S08##

Well it's physical. (Long pause) punching, kicking, he tries going for your throat. He uses anything around as well. **(CODE D2).**

ISR01##

Does having a brother with autism affect your life?

##S08##

Quite a lot.

ISR01##

How?

##S08##

Well (pause) if I am in the house I don't feel like free to do what I want, because obviously if he is like around and stuff like that, I am a bit older than him and I want to be like doing other things. **(CODE D2).**

ISR01##

What advice would you give to other children/young people who have a brother/sister with autism?

##S08##
That's a really hard question (long pause). I guess it depends on what their situation is. Like if it's an older brother then obviously try to be a bit more careful because obviously if they are a bit bigger than you then it could be a big problem. If they are younger then it's not as much as a problem but it still could be. I guess you just have to be really careful about what you say. (CODE D2).

ISR01##
I understand. What do other people think of (insert name of sibling with autism)?

##S08##
He can be selfish and just difficult. He is so unpredictable. You never know what's going to make him spark off. (CODE F3).

ISR01##
How would things be different if (insert name of sibling with autism) did not have autism?

##S08##
It would be a lot easier. Like I said in the mornings we have to tip toe around him because that is when it is at its worst like during school time. (CODE C2). Obviously in the holidays he gets up when he feels like it. We wouldn't have to tip toe around him and hope that he doesn't get out of control. I don't know what it would be like (pause) .I don't like the word normal either. (=name of sibling with autism=) is just (=name of sibling with autism=) and it's hard to imagine him without the autism because I sometimes think the autism takes up so much of him. (CODE D3). I don't know what he would be like without autism or how we would be together. I don't do things as much with him. He likes his football I like looking at stats and stuff. We have nothing in common really. I find that difficult and maybe that might be different if he didn't have autism. (CODE D2). Maybe we might do more as a family too. (CODE D2). It's normally alright but we have to always do things that (=name of sibling with autism=) wants to do, and we all have to keep him happy. (CODE D2). I just usually stick my headphones on and if he has a tantrum I just don't hear it. (CODE E1).

ISR01##
Does (insert name of sibling with autism) affect you?

##S08##
Yes.

ISR01##
Can you tell me some more about how this affects you?

##S08##
Like in school (pause), he doesn't have many people to hang around with and he finds it hard to make friends, so he would hang around me which wasn't much of a help. I had my group of friends and he would hang around and be a bit over the top sometimes so they sort of distanced themselves from me. So I was just stuck with him literally clinging on so that was a bit of a pain. (Long pause) I haven't ever brought a friend home. I don't really keep friends because of my brother. (Pause) when he kicks off in the mornings I go to school and I am really worried because I don't know what he is going to be like. I can't concentrate then. That's the hard thing (pause) I just worry. It's like really emotional and mental really, especially the problems and fights at home. (CODE D2).

ISR01##
How do you cope?

##S08##
I just curl up in a ball and cry (CODE E2). (long pause) or talk to mum. (CODE E3). I feel quite low and depressed sometimes but it's not proper depression or anything I think. I just sometimes feel a bit down in the dumps. (CODE E2).

ISR01##

What do you tend to do when you feel low and depressed?

##S08##

I just take myself away and have some time. (**CODE E1**). Sometimes I try to help, it depends what's happening. Yesterday, he didn't flare up but he scratched dad's guitar. I think it was an accident. Dad obviously got angry and normally I just keep out of the way and somehow I would get involved (**CODE E3**). but not meaningfully and that's when he starts on me. But like yesterday he came for me for comfort which is really unusual. Another time I can think of is when he actually did start was last time last week during the morning he was just proper wound up (pause) you know how you get those extreme highs and extreme lows. He was very hyper and I told him to stop and he got really peeved about that. It was only me and mum here (pause) Dad was at work. I took it upon myself to stop him because normally mum does it. I just thought I should give mum a break this morning, she doesn't need it constantly. I stopped him and anyway I normally have to hold him for ages and ages (pause) like hours on end. (**CODE E3**).

ISR01##

That sounds really difficult. So it seems like you are saying that sometimes you try to help and intervene and then sometimes you ignore and avoid the situation (pause)is that right?

##S08##

Yes exactly. I try to keep myself out (pause) like away from it, but sometimes (pause) normally I end up (pause) not by my own ways, but because of him I sometimes get involved. (**CODE E3**).

ISR01##

How does this make you feel?

##S08##

I feel a mix of things and lots of emotions (pause) like anger (long pause) totally upset and totally in like a whirlwind of emotions. Normally I end up showing tears really more than anything. During and after. (**CODE D2**).

ISR01##

I understand some of this can be quite difficult to talk about and you are doing really well.

##S08##

Yeh...thanks.

ISR01##

Ok. So when these things happen (pause) are you able to get help and support?

##S08##

Well I used to go to a counsellor in school, (**CODE G1**) for a little while. That was ok. Other than that, mum is the only person I would actually turn to. (**CODE G2**).

ISR01##

So you tend to talk to mum?

##S08##

Yes she really understands and I don't want other people to know it won't do any good for him if people spread things around about him. (**CODE G2**).

ISR01##

I see. In what ways could be more support or help for you or other siblings of children with autism?

##S08##

Well I guess something like you are doing now. This has been like therapy and I have enjoyed talking about this and I haven't ever had a chance to do this.(**CODE G3**). People always come in and there are always people coming for him, or mum and dad. There is never anyone for me. As well, like if there was more research on the psychological effects of people (pause) like

family who are affected. Also (pause) maybe groups who meet and talk like just for us. It would have helped to know more about it too (pause) like about autism. (**CODE G3).**

ISR01##
I see. You seem to have lots of good ideas. Do you think (insert name of sibling with autism) will affect your future?

##S08##
It might affect my future. He won't ever be able to have his own house and drive and have a job and kids and stuff. I may have to take him in one day. (**CODE H2)** I really don't know what the future holds you know, (pause) nor does anyone else.

ISR01##
How does this make you feel?

##S08##
I'd be quite worried because by that point he is going to be quite big and quite strong. I mean he is strong now you know. As it is I can just about contain him and even dad has trouble. When he is older he might be more difficult he might lose control or get worse. If he gets any worse or any stronger he is going to be really difficult to handle. (**CODE H1)**

ISR01##
I understand. We have come to the end of the interview now. Is there anything else that you would like to add?

##S08##
No. That's all fine.

ISR01##
No that's it. Thank you for taking the time to talk to me today.

##S08##
No it's ok. I am quite bored at the moment, so it's nice to talk to someone who understands how hard it is. People are always coming here for my brother, so it's good to have someone here for me.

ISR01##
Thank you.

END OF INTERVIEW
(1 AUDIO FILE (08) TOTAL INTERVIEW TIME 44.01 MINUTES)
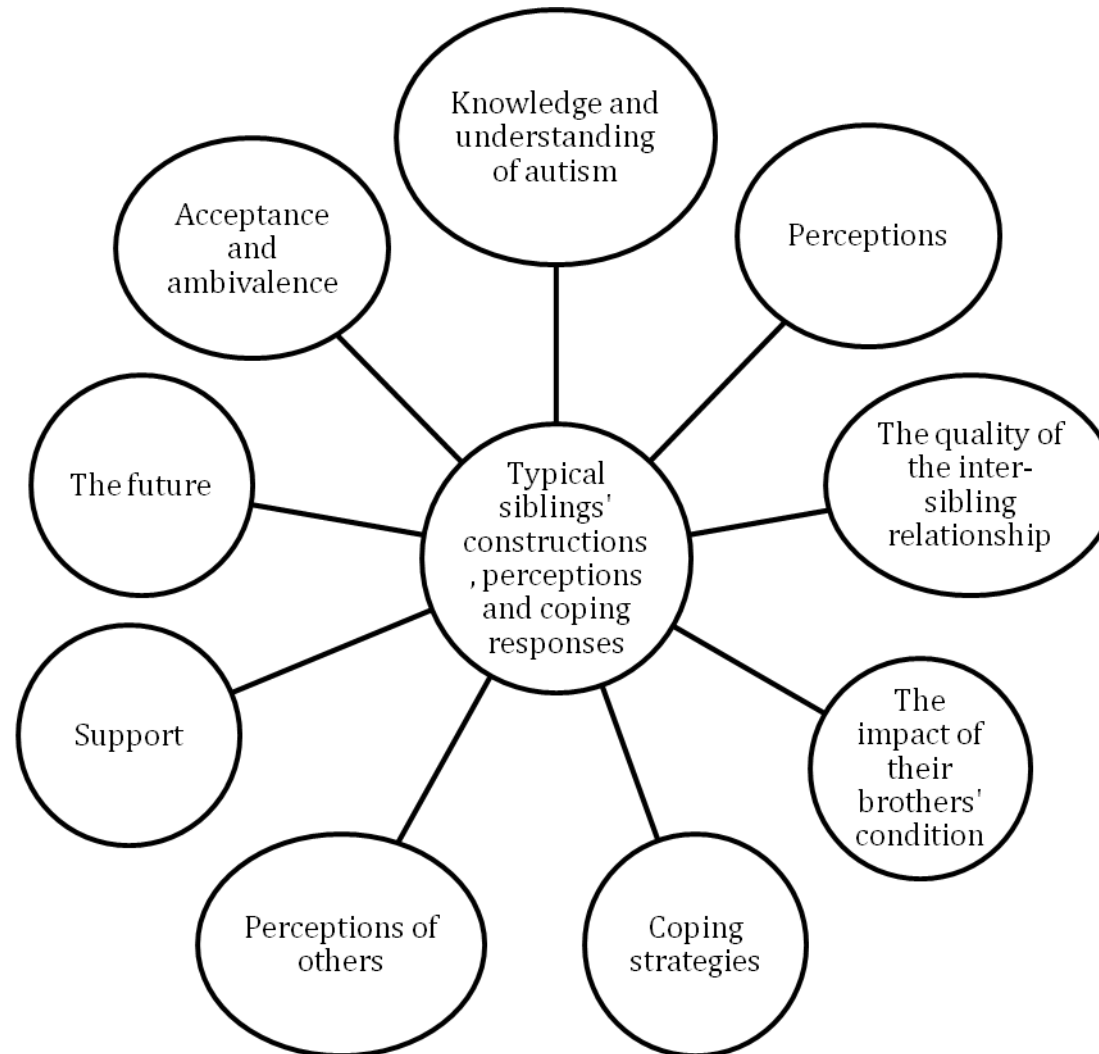
Appendix Eleven: Thematic maps for specific themes
Theme one: Knowledge and understanding of autism

Theme two: Perceptions

Theme three: The quality of the inter-sibling relationship

| | | Positive. |
| | | Participant constructs the inter-sibling relationship in a positive manner. |

The quality of the inter-sibling relationship.

| | | Negative. |
| | | Participant constructs the inter-sibling relationship in a negative manner. |

Theme four: The impact of their brothers' condition

```
┌─────────────────────┐                          ┌──────────────────────────┐
│                     │                          │        Positive.         │
│  The impact of their│─────────────────────────│ Participant views his/her │
│  brothers' condition.│                         │ brother has a positive    │
│                     │                          │ impact on his/her life.   │
└─────────────────────┘                          └──────────────────────────┘
```

Positive.

Participant views his/her brother has a positive impact on his/her life.

Negative.

Participant views his/her brother has a negative impact on his/her life.

Loss of a typical sibling.

Participant demonstrates a sense of loss/grief and recognises that they do not have a typically developing sibling.

The impact of their brothers' condition.

Theme five: Coping
strategies

Problem focused.

Participant adapts behaviour in an attempt to cope.

Coping strategies.

Appraisal focused.

Participant adapts cognitions in an attempt to cope.

Emotion focused.

Participant attempts to manage hostile and difficult emotions (e.g., disclaiming, escape-avoidance, accepting responsibility/blame, exercising self-control, seeking social support and positive reappraisal).

Theme six: Perceptions of others

Perceptions of others.

Negative.

Participant constructs that others demonstrate negativity toward his/her brother.

Theme seven: Support

Support.

Formal support.

Participant expresses they have accessed formal support.

Informal support.

Participant expresses they have accessed informal support.

Identified need for support.

Participant identifies a need for additional support.

No desire for support.

Participant expresses no desire for formal/informal support.

Theme eight: The future

Concerns about caretaking responsibilities in the future.

Participant expresses concerns about future caretaking responsibilities.

Concerns about impact on self in the future.

Participant expresses concerns about the impact his/her brother will have on their self in the future.

The future.

No concerns.

Participant expresses no concerns about the future.

Theme nine: Acceptance and ambivalence

Acceptance and ambivalence.

Acceptance.

Acceptance of autism as a part of his/her brother.
Acceptance of his/her brothers' condition as a feature of the inter-sibling relationship.
Acceptance of the impact of his/her brothers' condition.
Perception that others accept his/her brother.
Acceptance of caring responsibilities and impact on self in the future.

Ambivalence.

A discrepancy between acceptance of autism and a desire for change.

A discrepancy between acceptance of his/her brother's condition as a feature of the inter-sibling relationship and a desire for change.
A discrepancy between acceptance and a desire for change, as a result of the impact of his/her brothers' condition.
Ambivalence in relation to perceptions of others.
Acceptance of caring responsibilities and impact on self in the future.

Appendix Twelve: Definitions of codes

Theme	Code	Definition of Code
(1). Knowledge and understanding of autism.	(A1). No knowledge.	*Participant displays no knowledge of autism.*
	(A2). Psychological.	*Participant characterises autism by psychological/mental impairments.*
	(A3). Behavioural and psychological.	*Participant characterises autism by some psychological impairment, and by some behavioural characteristic(s).*
	(A4). Behavioural.	*Participant characterises autism by behavioural difficulties.*
(2). Perceptions.	(B2). Negative.	*Participant demonstrates he/she has a negative construction of his/her brother.*
	(B3). Positive.	*Participant demonstrates he/she has a positive construction of his/her brother.*

(3). The quality of the inter-sibling relationship.	(C1). Positive.	*Participant constructs the inter-sibling relationship in a positive manner.*
	(C2). Negative.	*Participant constructs the inter-sibling relationship in a negative manner.*
(4). The impact of their brothers' condition	(D1). Positive	*Participant views his/her brother has a positive impact on his/her life.*
	(D2). Negative.	*Participant views his/her brother has a negative impact on his/her life.*
	(D5). Loss of a typical sibling.	*Participant demonstrates a sense of loss/grief and recognises that they do not have a typically developing sibling.*
(5). Coping strategies.	(E1). Problem focused.	*Participant adapts behaviour in an attempt to cope.*
	(E2). Appraisal focused.	*Participant adapts cognitions in an attempt to cope.*
	(E3). Emotion focused.	*Participant attempts to manage hostile and difficult emotions (e.g., disclaiming, escape-avoidance, accepting responsibility/blame, exercising self-control, seeking social support and positive reappraisal).*

(6). Perceptions of others.	(F3). Negative.	*Participant constructs that others demonstrate negativity toward his/her brother.*
(7). Support.	(G1). Formal support.	*Participant expresses they have accessed formal support.*
	(G2). Informal support.	*Participant expresses they have accessed informal support.*
	(G3). Identified need for support.	*Participant identifies a need for additional support.*
	(G4). No desire for support.	*Participant expresses no desire for formal/informal support.*
(8). The future.	(H1). Concerns about caretaking responsibilities in the future.	*Participant expresses concerns about future caretaking responsibilities.*
	(H2). Concerns about impact on self in the future.	*Participant expresses concerns about the impact his/her brother will have on their self in the future.*
	(H3). No concerns.	*Participant expresses no concerns about the future.*

(9). Acceptance and ambivalence	(B1). Acceptance.	*Acceptance of autism as a part of his/her brother.*
	(B4). Ambivalence.	*A discrepancy between acceptance of autism and a desire for change.*
	(C3). Acceptance	*Acceptance of his/her brothers' condition as a feature of the inter-sibling relationship.*
	(C4). Ambivalence	*A discrepancy between acceptance of his/her brother's condition as a feature of the inter-sibling relationship and a desire for change.*
	(D3). Acceptance	*Acceptance of the impact of his/her brothers' condition.*
	(D4). Ambivalence.	*A discrepancy between acceptance and a desire for change, as a result of the impact of his/her brothers' condition.*
	(F1). Acceptance.	*Perception that others accept his/her brother.*

(H4). Ambivalence.	*A discrepancy between acceptance of future caring responsibilities and impact on self as well as a desire for change.*
(H5). Acceptance.	*Acceptance of caring responsibilities and impact on self in the future.*