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The Psychological Adjustment of Siblings of Children with Disabilities: The Role of School Factors

by

Francesca Leach

Thesis for the degree of Doctorate in Educational Psychology

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ABSTRACT

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THE PSYCHOLOGICAL ADJUSTMENT OF SIBLINGS OF CHILDREN WITH DISABILITIES: THE ROLE OF SCHOOL FACTORS

Francesca Leach

Previous research investigating the psychosocial wellbeing of siblings of children with a disability presents as contradictory and inconclusive. Explanations for the diverse findings have included the presence of different risk and protective factors, and methodological challenges faced by sibling research. This has included the combining of siblings of children with different disabilities into one group.

A systematic review was carried out to explore the psychological adjustment of two specific sibling groups; siblings of children with Autism Spectrum Condition (ASC) and siblings of children with Down syndrome (DS), aged 7 to 11, and the factors associated with such adjustment. Findings suggest that siblings do not automatically experience adjustment difficulties; however, a subgroup of children, particularly siblings of children with ASC, may be vulnerable to poor psychosocial wellbeing. Family factors, particularly parental wellbeing may be related to sibling adjustment, as may multiple demographic factors when considered as part of a risk scale. Results, however, need to be viewed with caution due to methodological drawbacks in the literature. Further research is required to explore factors across different ecological levels including wider societal factors.

The empirical paper sought to address some of the gaps in the existing research identified in the review. Specifically, the association between sibling adjustment and three school level factors, identified in the resilience literature, was considered. Information packs were distributed to prospective participants by professionals, support groups and schools. Parents and siblings of children with DS (n=76), ASC (n=72), and siblings of typically developing children (n=56), who participated completed a series of questionnaires measuring siblings emotional and behavioural adjustment, sense of school belonging, teacher relationship and peer loneliness. Results showed 32 (44.4%) siblings of children with an ASC and 27 (35.5%) siblings of children with DS had an adjustment difficulty of clinical significance. This compared to 17% of siblings of children with no disability. No school level factors were found to predict sibling adjustment. Reasons for this finding are discussed alongside implications for practice.

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DECLARATION OF AUTHORSHIP

I, Francesca Leach declare that the thesis entitled 'The Psychological adjustment of siblings of children with disabilities: The role of school factors' and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission.

Signed: ……..

Date:…….

Acknowledgements

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My sincere thanks and appreciation goes to all the parents and children who participated in this research and made this project possible. I would also like to thank all the services that helped me with data collection; along the way I have met and spoken to many passionate individuals whose desire and enthusiasm to support families of children with a disability has been inspirational.

I would like to express my gratitude to my friends and family for all the love and encouragement they have given me over the past three years. In particular to my friends for reminding me that there is world outside, and my family for keeping me fed and watered – I promise I will now learn to cook. I would also like to thank my parents for always having absolute faith in my ability to succeed. Without this love and support I would never have been able to progress this far in my academic and professional career.

This thesis is dedicated to a very special young boy, who has not only inspired my interest in working with children with Down syndrome, but taught me valuable lessons in determination and provided me with frequent reminders of the importance of taking time to having fun in life – thank you Jack.

Definitions and Abbreviations

APA	American Psychiatric Association
ASC	Autism Spectrum Condition
CBCL	Child Behaviour Checklist
CDI	Children's Depression Inventory
DS	Down syndrome
DSM	Diagnostic and Statistical Manual of Mental Disorders
EP	Educational Psychologist
ID	Intellectual Disability
M	Mean
N	Number of participants
NAS	The National Autistic Society
PDD	Pervasive Developmental Disorder
SD	Standard deviation
SDQ	Strengths and Difficulties Questionnaire
SE	Standard error
SEB	Social emotional behavioural
SEN	Special Educational Needs
SOSB	Sense of School Belonging
TD	Typically Developing
Z	z-score
$\chi 2$	Chi square test value

Chapter 1: Review Paper

The Psychological Adjustment of Siblings of Children with Autism Spectrum Condition and Down syndrome: A systematic review of the literature

Word Count: 10340

Research suggests that families of children with disabilities are often faced with unique challenges and rewards (Dykens, 2005; Mulroy, Robertson, Aiberti, Leonard & Bower, 2008;Schuntermann, 2007). Historically the literature has focused mainly on the way in which parents adjust and adapt to these experiences (e.g. Griffith et al. 2011; Lloyd & Hastings, 2008; Lloyd & Hastings, 2009; Boyd, 2002), with considerably less attention given to the adjustment and wellbeing of siblings of children with disabilities (Cuskelly, 2009;Tomeny, Barry & Bader, 2012). The relative dearth of studies considering the adjustment of siblings is contrary to the family perspective, according to which, families are interrelated and thus what affects one family member affects the whole system and all individuals within the system (Cox & Paley, 1997, 2003).

The current review and paper focuses on the adjustment of siblings of children with a disability.

Definition of Adjustment

To date, there is no single definition or measure of sibling adjustment in the disabled sibling literature. However there has been some overlap in the constructs explored. In particular previous research has focused on the behaviour of siblings. Research suggests that behaviour difficulties can manifest either internally (e.g., anxiety and depression) or externally (non-compliance, conduct problems, verbal aggression) and thus both behavioural have been considered (Achenbach & Edelbrock, 1983; Mash & Wolfe, 2002; Rossiter & Sharpe, 2001). Of late, researches have contended that sibling psychological adjustment encompasses dimensions beyond externalising and internalising behaviours (Moore & Keyes, 2003). This includes the notion of how children perceive themselves (Mash & Wolfe, 2002; Moore & Keyes, 2003). This is referred to as self-concept, and encompasses knowledge and evaluation of one's own values, qualities and strengths. Self-concept is closely related to self-esteem, which has been defined as one's own judgement of self-worth (Berk, 2006; Mash & Wolfe, 2002). Lastly, the development of peer relationships and social competence constitutes another area, which has started to be explored (Mandleco, Olsen, Dyches, & Marshall, 2003)

Given the previous areas of adjustment explored, throughout this review, and subsequent empirical paper, adjustment will be defined in terms of behaviour adjustment, self-concept and social competence. This will be referred to as social, emotional and behavioural wellbeing (SEB wellbing). The following terms will be used interchangeably: psychosocial wellbeing, adjustment, psychological wellbeing and social, emotional and behaviour adjustment. This represents the range of terms used within the existing literature.

Sibling Research

The limited research that has considered the wellbeing of siblings of disabled children presents as contradictory and inconclusive (e.g. Benson & Karlof, 2008: Meadan, Stoner & Angell, 2009). While some research has found siblings to be well adjusted (Orsmond & Seltzer, 2009) and even enriched by their experience (Findler & Vardi, 2009; Hastings, 2003b; Macks & Reeve, 2007) other researchers have found siblings to be vulnerable to poor psychological wellbeing, including internalising and externalising problems (e.g. Jones, Welsh, Glassmire & Tavegia, 2006; Rossiter & Sharpe, 2001; Verte, Buyss & Buysse, 2003). The mixed findings make it difficult to establish which siblings require support and how best to provide this support (Giallo, Robers, Emerson, Wood & Gavidia-Payne, 2014).

Numerous explanations have been offered for the diverse findings reported by researchers, including the methodological challenges faced by sibling research (e.g. Hodapp, Glidden & Kaiser, 2005; Stoneman, 2005). In particular it has been noted that much of the research exploring the adjustment of siblings has reported on the siblings of mixed disability groups (Cuskelly, 2009; Hodapp et al., 2005). Yet several researchers have suggested that specific characteristics associated with different disabilities may influence sibling adjustment (Hodapp et al., 2005; Wolf, Fisman, Ellison & Freeman, 1998). Specifically, it has been noted that siblings of children with an Autistic Spectrum Condition (ASC) may be at greater risk of poor psychosocial adjustment when compared to siblings of children with other disabilities, including Down syndrome (DS) (Fisman, Wolf, Ellison & Freeman, 2000; Fisman, Wolf, Ellison, Gills, Freeman & Szatmari, 1996; Rodrigue, Geffken & Morgan, 1993). This blanket treatment of siblings of children with different disabilities may therefore act as a significant confounding variable across studies.

Given the suggestion that the presence of different disabilities may impact on the adjustment of siblings differently, a key aim of this review and subsequent empirical paper is to consider the wellbeing of two specific sibling groups: siblings of children with an ASC and siblings of children with DS. These two sibling groups were chosen due to potential differences in experience for siblings. For example it has been suggested that the significant social and communication deficits associated with ASC may impact on sibling relationships, in a way which is different to the effect of having a siblings with a developmental disability where siblings are more social (Pollard, 2013; Jahromi, Gulsrud & Kasari (2008)). In addition, it was also acknowledged, that given that research within the sibling domain is still within its infancy, it was advantageous to make a comparison between groups where there is already a body of literature available to be guided by. Thus far whilst some research has specifically considered the wellbeing of siblings of children with ASC, siblings of children with DS have received limited research attention.

A brief overview of these two disabilities is provided below.

Autism Spectrum Condition (ASC)

Originally described by Leo Kanner in 1943, ASC is a complex neurodevelopmental disorder (Kanner, 1943). Individuals with an ASC present with impairments in three key domains of development: (i) social interaction, (ii) verbal and nonverbal communication, and (iii) the presence of repetitive and restricted patterns of behaviour, interests and activities (APA DSM IV, 2000; APA DSM 5, 2013; Happé & Ronald, 2008). Given the wide variability in the way in which symptoms and characteristics present ASC is considered a spectrum condition, ranging from mild to severe (Geschwind, 2011).

At present the cause of ASC is unknown. Instead the condition is attributed to numerous factors, rather than one single cause (see Geschwind, 2011). This includes the suggestion of a strong genetic component (see Newschaffer et al. 2007; Geschwind, 2011). Within recent years, the term ‘Autism Spectrum Condition’ (ASC) has become favoured, recognising that whilst individuals may have a disability there are also areas of cognitive strength (Baron-Cohen, Scott, Allison, 2009). Throughout this paper the term ASC is used as the term of preference,

however Autism Spectrum Disorder (ASD) and Autism will also be used, interchangeably, recognising that other terms are still frequently used.

Down Syndrome (DS)

First described by John Langdon in 1866, DS is the most common cause of moderate to significant intellectual disability (Sherman, Allen, Bean & Freeman, 2007). Diagnosed by chromosomal analysis, DS is a genetic disorder which in most incidences, is caused by the addition of a third chromosome 21 in all cells (Roizen & Patterson, 2003; Sherman et al., 2007). A number of health complications are associated with DS; including congenital heart disease (50%), hearing impairments (75%), sleep apnoea (75-50%) and eyesight problems (50%) (Bull, 2011; Roizen and Patterson, 2003).

Theoretical Framework - Risk and Resilience

Theory of resilience. In an effort to account for the variation in sibling adjustment several researchers have drawn upon resilience theory (e.g. Bellin & Kovacs, 2006; Fisman et al., 1996). This theory details how it is possible for children who are exposed to similarly adverse circumstances to have divergent psychosocial outcomes with only some developing mental health problems (Greene, 2002). That is, some children show resilience; " the capacity to adapt despite challenging or threatening circumstances" (Masten, Best & Garmezy, 1990, p.426). According to the resilience theory, it is the presence and interaction of protective factors that can remove or reduce the detrimental effects created by risk factors (Fraser & Terzian, 2005; Masten & Obradovic, 2006; Werner & Smith, 1989). Thus within the sibling literature it is suggested that that the variability in the adjustment of siblings is in part related to the presence of specific risk and protective factors (Tomeny et al., 2012).

Ecological Systems Theory. According to the Ecological Systems Theory (Bronfenbrenner, 1979, 1986, 1994) a child's development is shaped and influenced by five environmental subsystems (Microsystem, Mesosystem, Exosystem, Macrosystem and Chronosystem), within which the child exists (see Figure 1). Therefore, in order to understand an individual's development, consideration needs

to be given to the complex interactions and relationships across, and within each of these systems (Bronfenbrenner, 1986).

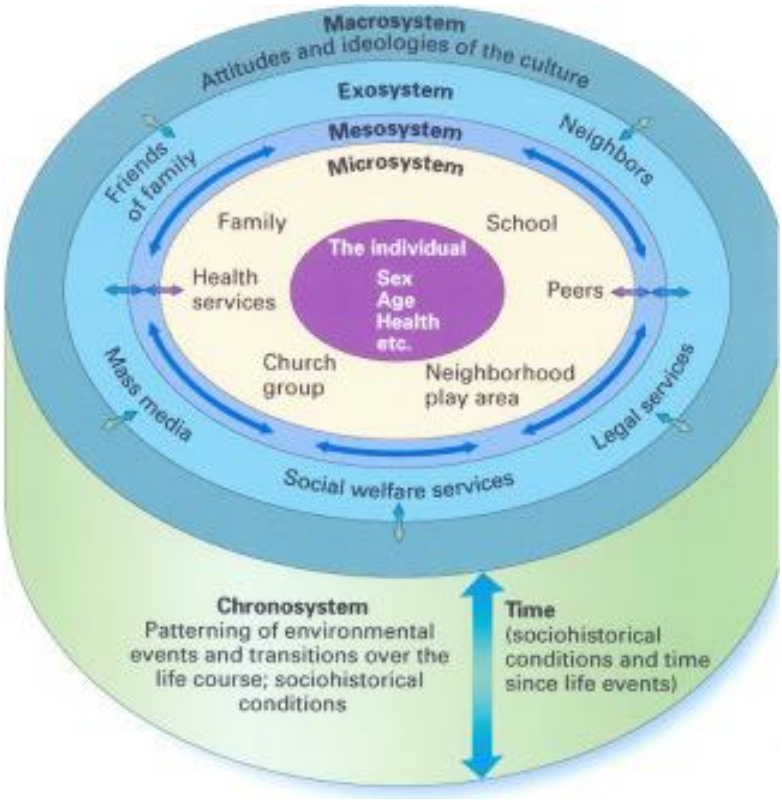


Figure 1: Bronfenbrenner's Ecological Systems Theory

Several researchers have used Ecological Systems Theory as a lens through which to investigate the principles of risk, resilience and protection (Fraser, Kirby, Smokowski, 2004; Jenson & Fraser, 2011). This framework suggests that risk and protective factors may exist at all levels of a child's ecology, and therefore when considering the adjustment of siblings, consideration needs to be given to variables at each of the different layers (Jenson & Fraser, 2011). This theoretical framework is presented below (see Figure 2).

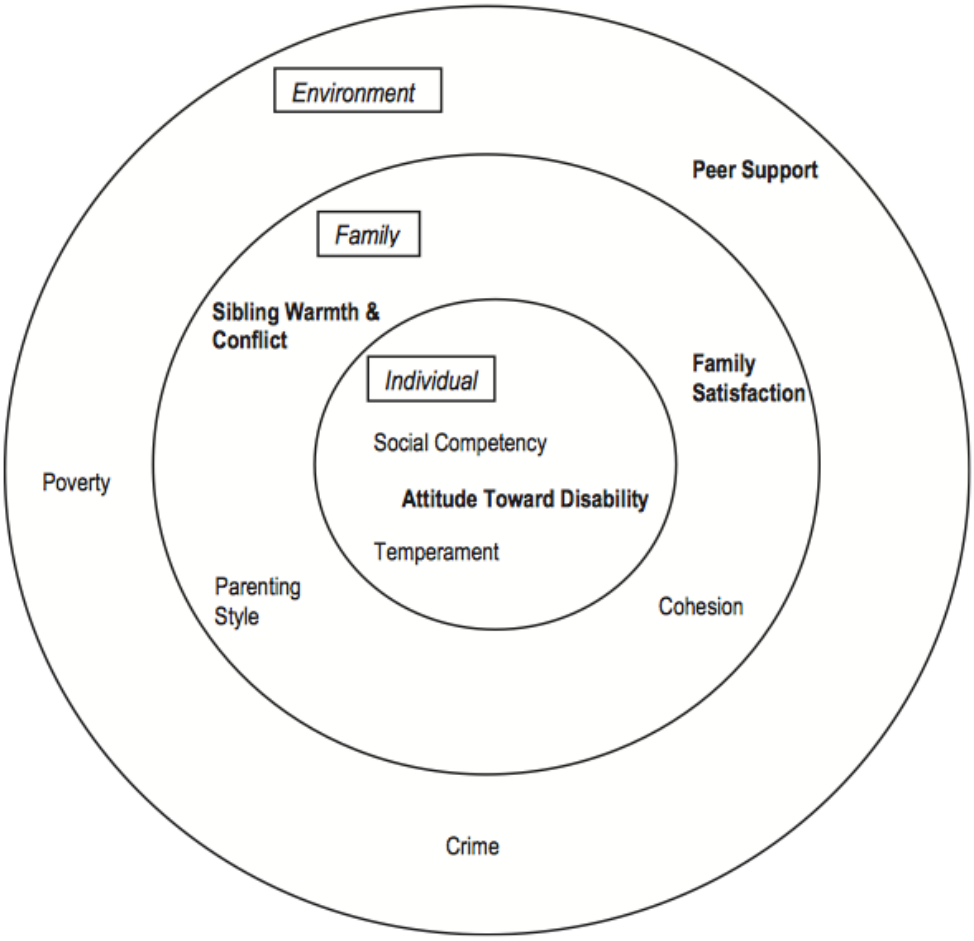


Figure 2: Application of a social ecological framework to the study of sibling adjustment. Figure from Bellin, Bentley and Sawin (2009); Printed with permission.

Psychological Correlates

As noted previously, studies have started to investigate factors that may be associated with siblings psychosocial wellbeing (e.g. Cuskelly, Chant & Hayes, 1998). This has included factors that relate to the individual sibling, for example, coping style (Ross & Cuskelly, 2006) and age (Bagenholm & Gillberg, 1991), and family factors, for example parental stress (e.g. Cebula, 2012; Giallo & Gavidia-Payne, 2006) and presence of social support (e.g. Hastings, 2003b). As with research considering sibling adjustment, results considering the association with different variables are mixed with a clear understanding of contributing factors yet to emerge (Bellin et al., 2009; Meadan et al., 2010).

Fisman et al., (2000) suggests that given the potential difference in outcome for siblings of children with different disabilities, there may be unique predictors of adjustment specific to different sibling groups. The second aim of this review is therefore to consider variables which impact on the adjustment of two specific sibling groups; siblings of children with an ASC and DS. Understanding the specific risk and protective factors for different sibling groups may have important implications for intervention work.

Aims and Scope of Literature Review

This review aims to understand the social, emotional, and behavioural (SEB) adjustment, and factors related with the adjustment, of siblings of children with an ASC or DS. More specifically, the review seeks to answer the following questions:

1. To what extent does having a brother or sister with Autism Spectrum Condition (ASC) or Down Syndrome (DS) affect the social, emotional and behavioural (SEB) adjustment of siblings aged 4 to 21 years?

2. What factors are associated with the adjustment of siblings of children with an ASC or DS?

In order to answer these questions, a systematic review of the literature was conducted. Evidence from each study is summarised and critically considered, gaps in the literature identified, and proposals made for the direction of future research.

Review Methodology

Search Strategy

An initial search of the literature was conducted using the electronic databases PsychInfo (via EBSCO; 1887-2013) and Web of Science (via Web of Knowledge, 1950-2013). Searches were limited to English Language and peer-reviewed papers. The researcher generated the original search terms, with further terms generated in the thesaurus from each database. Once a relevant article was found, if the key words used to categorise it were appropriate they were added to the list of search terms (see

Appendix B for search terms). In addition, the reference lists of included papers were hand-searched for additional relevant studies.

Study Selection

The searches of electronic databases and reference lists produced 466 results. The titles and abstracts for all paper were screened against predetermined inclusion and exclusion criterion (see Appendix C). A total of 380 papers were removed, due to not meeting the criteria. Full texts of the remaining papers were sought and screened and, of these, 33 were deemed to satisfy the set criteria (Figure 3).

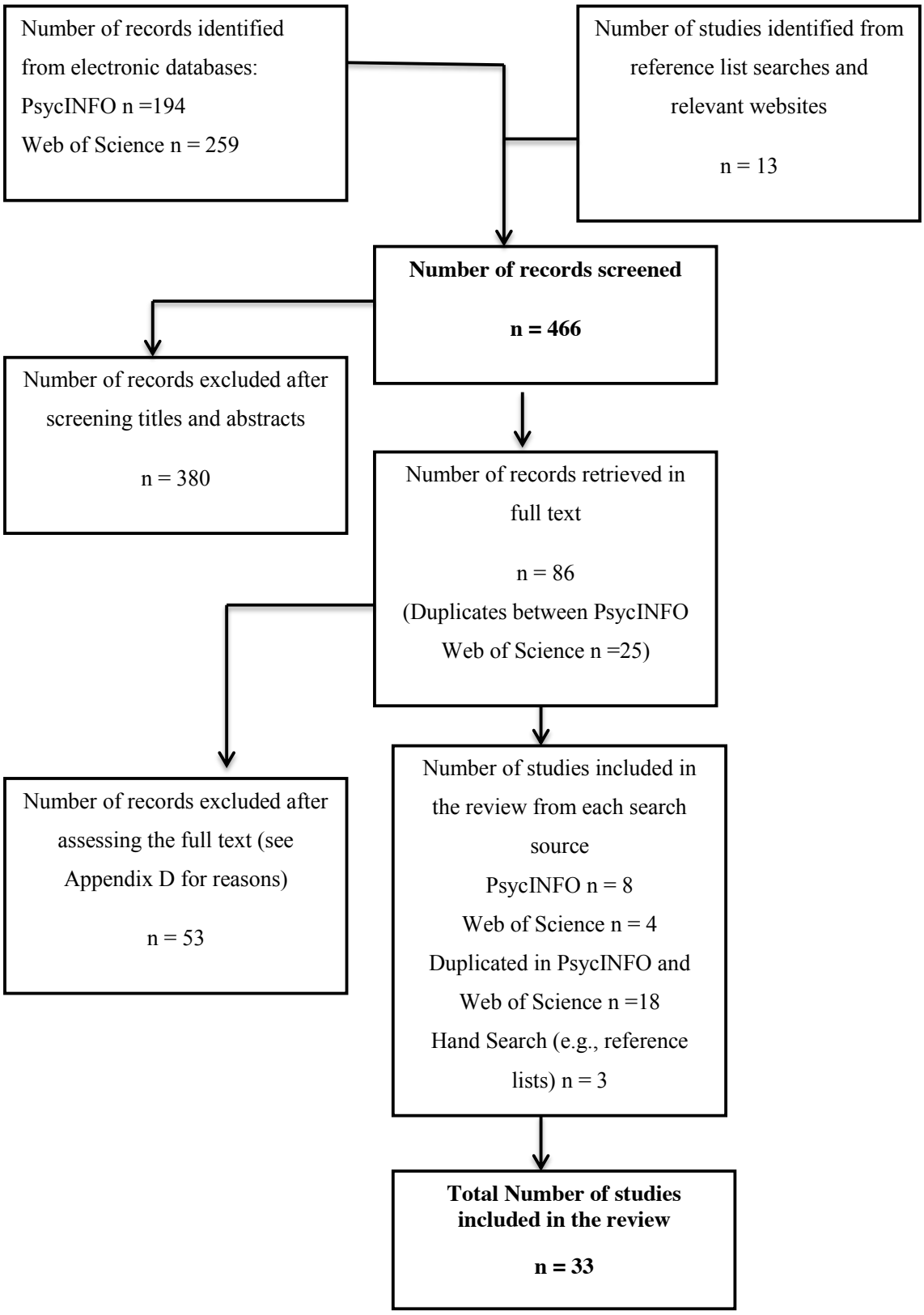


Figure 3: Flow chart showing the results of the systematic search process

Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria were applied:

Participants. Studies were included if the focus of the study was the typically developing (TD) sibling of an individual with ASC or DS. These children are hereon referred to as 'Target Siblings.' Target siblings were aged between 4 and 19. Studies that included very young siblings of children with an ASC or DS were not included as in the ASC sample there is a tendency for the primary goal of these studies to investigate whether or not siblings are 'at risk' of an ASC (e.g. Yirmiya, Gamliel, Pilowsky, Feldman, Baron-Cohen & Sigman, 2006).

Studies were eligible for inclusion if they included a child with either an ASC or DS aged 4-21. These children are hereon referred to as 'Reference Siblings.' The age of the reference sibling was chosen as by this age it is likely that the disability would be apparent in everyday functioning, thus ensuring that siblings were aware of their brothers or sisters disability.

Only paper with participants recruited from North America, Europe and Australia were included. These continents were selected based upon their cultural similarities.

Study design. Studies were eligible for inclusion if they were described as an original data based study and included studies employing either a quantitative or qualitative methodology. Studies were included regardless of whether they included an active, passive or no control group. Case study designs were not included.

Outcome variables. Studies were eligible for inclusion if they focused on the SEB adjustment, or variables associated with the adjustment, of TD siblings of children with ASC or DS. Therefore studies which focused solely on sibling relationships (e.g. Rivers & Stoneman, 2008) were excluded whilst studies which consider how sibling relationships impact on sibling adjustment were included (e.g. Pollard, Barry, Freedman & Kotchick, 2013).

Date. Studies were eligible for inclusion if they were published after 1978. This was in recognition of the publication of the Warnock Report (Special

Educational Needs [SEN]; 1978), which led to changes in how SEN was conceptualised and thus seemed a suitable start point for this historical investigation.

Publication requirement. Papers were included if they were published in a peer-reviewed journal and written in English. Therefore unpublished work such as dissertations, conference presentations and review articles were excluded.

Data extraction

Study characteristics

Samples. A total of 33 studies were included in the review with n=22 (67%) focusing on siblings of children with an ASC, n= 5 (15%) focusing on siblings of children with DS and n =6 (18%) focusing on siblings of children with ASC and siblings of children with DS. These studies are outlined in Appendix A.

Sample sizes for quantitative studies investigating the adjustment of siblings of children with an ASC range from small (n=7) [27] to large (n=486) [7], with three studies reporting sample sizes over 50 and four studies over 100. Qualitative studies had sample sizes from 8 participants [22] to 12 participants [20].

Studies addressing the adjustment of siblings of children with DS ranged from small (n=19) [28] to moderate (n=95) [8], with 3 studies having sample sizes over 50. No studies reported power estimates in terms of sample size selection.

Participants. Across studies 2336 siblings participated (79% siblings of children with an ASC, 21% siblings of children with DS). There was an approximately equal mix of female and male target siblings of children with an ASC (male = 45%, female = 49% female, unknown = 6%) and DS (male = 41%, female = 50%, unknown = 9%). Studies included a higher proportion of male children with an ASC (male =73%, female = 14%, unknown = 13%), reflecting the higher ratio of males, compared to females with an ASC reported in the general population (Baron-Cohen et al. 2011). There were more equal proportions of male and female children with DS (male = 31%, female = 37%, unknown = 32%). See table 1 for further details.

Table 1

Number of participants in each group by gender

	ASD	**DS**	**Total**
	n	***n***	***n***
Target Siblings Total	1860	476	2336
Target Siblings Male	857	191	1048
Target Siblings Female	920	241	1161
Target Siblings gender not reported	83	44	127
References Siblings Total	1860	476	2336
Reference Siblings Male	1360	148	1508
Reference Siblings Female	251	174	425
Reference Siblings gender not reported	249	154	403

Note. n = number of siblings

In nearly 3 out of 4 studies (n=24), target siblings ranged in age from childhood to adolescence (aged 4 to 18 years). A further four studies included only children under 14 years, and two studies included adolescent siblings only (aged 12 years upwards).

Just over half of studies (n= 19) included only one TD sibling from each family and was most frequently the sibling closest in age. With the exception of gender and SES, few studies acknowledged the extent to which the sample was representative of the population from which they were drawn.

Recruitment strategy. Nearly two in three studies (n=21) recruited participants from support groups (e.g. ASC Society). The remaining 12 studies recruited participants from larger studies or an intervention group. Studies were conducted in five countries: 22% in the USA, 40 % within the UK, 15% in Australia, 19% in Canada, and 4% in Belgium.

Eligibility Criteria. There was variation in the criteria which siblings were required to meet in order to be eligible for inclusion in the study. 30% (n=10) of studies included participants irrespective of the reference siblings ASC diagnosis. For example reference siblings were included if they had a diagnosis of Autism, Pervasive Developmental Disorder (PDD), High Functioning Autism (HFA) or Asperger Syndrome. Two studies included siblings of children with HFA only (27, 32). Not all studies reported the specifics of the ASC diagnosis.

Several studies (n=3) permitted siblings to have additional needs, with the exception of the need of focus (ASC/DS), for example ADHD. Other studies required siblings to have no disability (n= 8). Not all studies (n = 22) reported the inclusion and exclusion criteria of TD sibling participants.

Research Methodology

Research design. 84% of studies (n=28) employed a quantitative cross-sectional design. Of the 5 other studies, 4 used direct interviews to explore sibling perspectives and one study evaluated sibling adjustment, pre and post involvement in a sibling support group. Two studies employed a mixed methods cross-sectional design. Three studies employed a repeated measure cross-sectional study design, which included a 3-year follow up. No qualitative studies considered the adjustment of siblings of children with DS.

The majority of studies (n=25), [75%] employed a comparison group. There was wide variation in the type of comparison group. See table 2 for specific details.

Table 2

Number of studies using different types of comparison groups

Type of comparison group	Group		
	Siblings of children with ASC	Siblings of children with DS	Total
	Number of studies		
Siblings of Children with no disability	10	8	18
Normative data	8	1	9
No comparison group	8	0	8
Children with a disability	0	1	1
Siblings of children with a disability other than an ASC of DS	2	1	3
ABA involvement vs no ABA *	1	0	1
Siblings of children with an ASC vs Siblings of children with DS	3	3	6

Note. *Applied Behaviour Analysis (ABA) is an intensive home-based intervention (see Fernandes & Amato, 2013)

The level of matching between control groups and experimental groups varied; numerous studies matched for demographics or used statistical analysis to ensure no significant demographic differences between groups. The factors on which participants were matched, and the number of factors varied between studies. One study matched on a case-by-case basis (5). One study (28) matched disabled children on mental age, as opposed to chronological age.

Data collection. Across all studies data was collected from a range of informants. 30% (n=10) of studies collected data from parents only and 12% (n=4) from siblings only. There was some triangulation of results, with 58% (n=19) of papers collecting data from multiple sources. This included 25% (n =8) of studies collecting data from parents and siblings, 15% of studies (n= 5) using data from parents and teachers, and 9% of papers (n =3) making a direct comparison between mothers and father responses. Lastly, 6% (n=2) collected data from parents, teachers and siblings, and 3% (n=1) from mothers, fathers and siblings.

Measures. All studies, with the exception of the 4 studies using a qualitative method, employed a standardised questionnaire or checklist pertaining to sibling adjustment. However there was some variation in the specific measure.

Seven studies considered the adjustment of siblings of children with an ASC using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). This measure was not used in studies considering the adjustment of siblings with DS. Ten studies focused on the adjustment of siblings of children with an ASC using the Achenbach Child Behaviour Checklist. The CBCL was also used by 5 studies addressing the adjustment of siblings of children with DS. Others used measures focused on more specific internalising behaviour such as anxiety or depression for example, The Children's Depression Inventory (Kovacs, 1983).

A few studies (n = 11) collected data that aimed to measure participant's perceptions of their own adjustment and skills, including measures of self-concept. The most frequently used measure was The Piers Harris Self Concept Scale (n= 6). All studies employing a qualitative methodology used semi-structured interviews.

Systematic Review Results

The results of this systematic review are organised in the following way. Firstly the psychological adjustment of siblings of children with an ASC and DS is considered. Outcomes are grouped into three concepts. These are: Emotional and Psychological Wellbeing, Social Competence and Peer Relationships, and Self Concept. This reflects the finding that all three domains have important bearing for the overall psychological wellbeing of children (Bond & Smith, 1996). Within these concepts the results are presented according to whether they focus on outcomes for

siblings of children with an ASC or siblings of children with DS. By presenting the results separately the aim was to highlight important differences in outcomes for siblings according to the disability of their brother or sister. Lastly results are loosely grouped according to the outcome measure used, allowing for consideration of how the use of different measures may impact on findings.

Secondly this review considers factors, which are associated with sibling adjustment. These factors are grouped according to different ecological levels, following the aforementioned suggestion of the importance of considering the interacting systems within which a child exists.

Complete details about the sample, design, measure and outcomes for each study can be found in Appendix A. A reference for each study is provided in number form (in brackets) throughout the results section, to ensure clarity. Table 3 shows authors names and the corresponding number.

Table 3

Paper number and corresponding author name and publication year

Paper Number	Author Name	Publication Year
1	Bagenholm and Gillberg	1991
2	Cebula	2012
3	Cuskelly, Chant and Hayes	1998
4	Cuskelly and Dadd	1992
5	Cuskelly and Gunn	1993
6	Cuskelly and Gunn	2006
7	Dempsey, Llorens, Brewton, Mulchandani & Goinkochel	2012
8	Gath and Gumley	1987
9	Gold	1993

10	Griffith, Hastings and Petalas	2014
11	Fisman, Wolf, Ellison & Feeman	2000
12	Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari	1996
13	Hastings	2003a
14	Hastings	2003b
15	Hesse, Danko & Budd	2013
16	Kaminsky and Dewey	2002
17	Macks and Reeve	2007
18	Mascha and Boucher	2006
19	Mates	1990
20	Moyson and Roeyers	2011
21	Orsmond and Seltzer	2009
22	Petalas, Hastings, Nash, Dowey & Reilly	2009
23	Petalas, Hastings, Nash, Dowey & Reilly	2012
24	Petalas, Hastings, Nash, Hall, Joannidid & Dowey	2012
25	Petalas, Hastings, Nash, Lloyd & Dowey	2009
26	Pollard, Barry, Feedman & Kotchich	2013
27	Roa & Beidel	2009
28	Rodrigue, Geffken & Morgan	1993
29	Ross & Cuskelly	2006
30	Smith & Perry	2004
31	Tomeny, Barry & Bader	2012
32	Verte, Roeyers & Buysse	2003
33	Wolf, Fisman, Ellison & Freeman	1998

Psychosocial Adjustment of Siblings

Adjustment of Siblings of Children with an ASC

SEB Adjustment - CBCL. Nine studies (7, 9, 16, 27, 28, 29, 30, 31, 32) considered the adjustment of siblings of children with an ASC using the CBCL as a measure of outcome. Two of these studies (29, 30) considered the percentage of children considered at risk according to predefined clinical scores. Of the remaining 7 studies, three revealed higher levels of internalising problems in target siblings than siblings of TD children (27, 28, 32). The inflated T scores (T>50) of the siblings within these studies suggest these differences to be due to poor sibling adjustment, as opposed to a particularly well-adjusted control groups. However whilst sibling scores were elevated, in all except one case, the mean scores of the sibling groups were within a non-clinical range (Achenback & Edelbrodk, 1983). The exception to this was one study (32), which found that 6-11 year old boys were reported to have borderline to clinically significant (T>60) levels of internalising behaviour. In contrast, four of the seven studies (7, 9, 16, 31) revealed target siblings to have no greater internalising difficulties than siblings of TD children, with both groups considered well adjusted. Moreover, one study (7) found siblings of children with ASC to show significantly fewer internalising problems, than in a normative sample. Effect sizes across studies ranged from small (d= 0.13) (7) to large (d = 2.08) (32). The smallest effect size was found by Dempsey, Llorens, Brewton, Mulchandani & Goin-Kochel (2012) (7) where siblings showed less internalising difficulties than a normative sample.

When considering externalising behaviour problems the results are similarly varied. Only two (28, 32) of the seven studies revealed siblings of children with an ASC to have significantly higher levels of internalising difficulties. In these studies, effect sizes were large (d=0.51 [28]; d = 2.44 [32]), although the scores were not considered clinically significant. As also found with internalising problems one further study (7) found a significant difference between groups, however in the opposite direction, with siblings reporting less externalising behaviour difficulties than a normative sample. The effect size was however small (d= 0.32). Four studies revealed no significant difference between siblings of children with a disability and

control siblings on the externalising domain of the CBCL (9, 16, 27, 31) with all siblings found to score within a non-clinical range.

Whilst the aforementioned studies considered sibling adjustment in terms of comparison to a control group, or the extent to which the samples mean scores were within a clinical or non-clinical range, two of the nine studies (29, 30) using the CBCL to look at adjustment in the ASC sibling group considered the proportions of siblings that were considered at-risk according to predefined clinical ranges. One study (29) reported 40% of target siblings to have a score on the CBCL internalising or externalising index that was within the at-risk or clinical range (T>60). This was despite the mean score of the ASC sibling group falling within the non-clinical range. Within this 40% a significantly higher proportion (65%) of siblings were found to have difficulties of an internalising nature compared to externalising. The authors (29) note that this is substantially higher than the 6% (Achenbach, 1991) to 13% (Sawyer et al. 2001) expected in a community sample. One other study (30) also reported a higher proportion of target siblings to experience internalising and externalising difficulties than would be expected in a community sample.

Most studies using the CBCL did not consider the proportion of siblings within clinical ranges and considered solely the mean score of each group thus making more direct comparisons difficult. Furthermore, study 30 evaluated a sibling support group, thus inflated levels of adjustment difficulties may be expected.

SEB Adjustment – SDQ. Whilst the aforementioned studies utilised the CBCL to consider adjustment in siblings of children with ASC, a further six studies (2, 10, 13, 14, 15 & 25) focused on the SEB adjustment of target siblings as measured by the parental version of SDQ. Four studies found that siblings of children with an ASC had significantly more adjustment difficulties than siblings of TD children on at least one domain of the SDQ, including total problems (10, 14, 15), emotional problems (10, 14, 25), conduct problems (10, 13) and problems of hyperactivity (14). Similar to the previously reported studies, one study (15) noted that although significant differences were found between groups, sibling scores were still within a ‘normal’ range. Effect sizes varied from d= 0.12 (25) to d= 0.50 (13) with the smallest effect size found for emotional problems and the largest for conduct difficulties.

In contrast one study (13) found that whilst siblings of children with an ASC differed significantly from the normative data on the SDQ (Meltzer, Gatward, Goodman & Ford, 2000) it was in the opposite direction, with target siblings reporting fewer total adjustment problems, as well as fewer emotional problems, conduct problems and problems of hyperactivity than found in a normative sample. It is worth noting that in this study the children with an ASC were engaged in ABA and thus may not be representative of most siblings of children with ASC. Effect sizes were noted to be small, with a range from d =0.04 to d= 0.36 across subscales.

Four of the six studies (2, 10, 14, 25) considered the proportion of siblings with SDQ scores that fell within an 'abnormal range.' Three studies (10, 14, 25) found that on at least one subscale of the SDQ, a higher proportion of siblings of children with ASC had scores considered of clinical significance than found in a normative sample. This included, a significantly higher proportion of siblings with clinically significant difficulties in the total adjustment domain (10, 14), emotional difficulties (10, 14, 25) and conduct problems (10, 14). Conversely, one study (2) found that the proportion of siblings of children with an ASC who scored in the 'abnormal' range on the SDQ was similar to what would be expected in a community sample (Meltzer et al., 2000; Goodman, 1997).

SEB Adjustment – Other measures. Eight studies investigated the adjustment of siblings of children with an ASC using an outcome measure other than the CBCL and SDQ (1, 11, 12, 9, 17, 19, 21, 26). As with the SDQ and the CBCL, results were mixed, with two studies noting no significant difference between the behavioural and emotional adjustment of target sibling, compared to normative data (19) or a control group (17). Meanwhile, another study of siblings of children with PDD (12) found significantly more internalising problems in both parent and teacher reports and significantly more externalising problems in parent reports when compared to siblings of children with no disability and siblings of children with DS. A similar pattern of findings was found at a 3 year follow up (11). Study 1 also reported increased behaviour difficulties in siblings of children with an ASC.

Three of the studies (9, 21, 17) considered the level of depression in siblings. One study (9) reported higher levels of depression in siblings of boys with an ASC compared to a control group. Moreover, the mean score of the target sibling group

fell within a clinically significant range, whilst the control group scored within a normal range (d=0.58). In contrast, however, the other two studies reported no significant difference between siblings and a comparison group on a measure of depression (17), and similar, if not lower, levels of depression in an adolescent sibling sample, than would be expected in community adolescent sample (21).

When considering the adjustment of siblings of children with an ASC, other reported outcomes included no significant differences in the level of self reported anxiety between siblings of children diagnosed with an ASC and siblings of children with DS (26) and anxiety levels in siblings of children with an ASC that are comparable to community sample (21).

Peer Relationships. Fourteen studies (1, 9, 10, 13, 14, 16, 20, 22, 23, 25, 27, 28, 31, 32) included in this review, investigated the impact of having a brother or sister with an ASC on peer relationships and social competence.

Six studies (9, 16, 27, 28, 31, 32) reported on the social adjustment of siblings, using the Social Problems and/or Social Competence subsection of the CBCL as an outcome measure. In all six studies no significant differences were found between siblings of children with an ASC and siblings of TD children. Similar findings were reported by studies that utilised the SDQ as a measure of peer relations. Indeed, only one study (14) found that siblings of children with an ASC were rated as having significantly more peer problems, compared to a normative sample, with three studies (13, 10, 25) reporting no significant difference between groups. In one study (25) this finding extended to include no significant differences in peer relationships between siblings of children with ASC and an Intellectual Disability (ID) and siblings of children with an ID only.

In contrast, one study (1) found a disproportionately high number of siblings (35%) of children with ASC to be reported by parents as having no friends and feeling lonely, whilst no siblings in the comparison group reported feeling lonely. Qualitative studies reported that some siblings experienced a sense of separation or isolation from friends, and at times were reluctant to invite friends over due to embarrassment about their sibling's disability (20, 22, 23).

Self Concept. Seven studies (1, 2, 17, 19, 27, 28, 32) considered the self-concept of siblings of children with an ASC. Three of these reported that compared to a normative sample (19, 17) or control group (32) siblings of children with an ASC had a significantly higher mean self-concept score, as measured by the Piers Harris Self Concept Scale (Piers & Harris, 1986) (19, 17) or SDQ (32). This suggests that target siblings may hold a more positive view of their self than siblings of non-disabled children. In all studies, this was considered a genuine inflation as siblings of children with no disability still scored within the average range, and thus the findings were not just the result of a poorly adjusted control group. Effect Sizes ranged from d =0.29 to d = 1.22 (32). Three of the studies (1, 2, 27) also using the Piers-Harris Children's Self Concept Scale (Piers & Harris, 1986) found no significant differences between siblings of control children and siblings of children with ASC. Mean scores for both control group siblings and siblings of children with an ASC were reported to be within the 'normal' range. Studies using other measures have also noted no significant difference between siblings of children with ASC and TD siblings on a measure of self-concept (28).

Adjustment of Siblings of Children with DS

SEB Adjustment. Eleven studies (3,4,5,6,8,11,12,16,26,28,33) considered the adjustment of siblings of children with DS. Five of these studies used the CBCL (3,6,16,28, 33), as an outcome measure. In four studies no significant differences were noted between siblings of children with DS and siblings of TD children in terms of internalising and externalising behaviour. All four studies noted that the mean scores (internalising, externalising, and where applicable total adjustment score) for siblings were within the non-clinical range. In contrast however Study 33 noted siblings of children with DS to have higher levels of internalising difficulties, but not externalising, when compared to siblings of TD children. However the inflation in internalising difficulties was not found at all time points. Only one study (6) reported the proportion of children to score above the clinical cut off point, and this did not differ significantly from the control group. The largest effect size was found for internalising difficulties r=0.56 (28).

Two studies (4, 5) used the Revised Problem Behaviour Checklist (RPBC, Quay & Peterson, 1987) as a measure of outcome. One study (4) noted that whilst the

mean scores of siblings of children with DS was not within the 'deviant' range, 43% of siblings showed some form of adjustment difficulty, according to at least one rater, on at least one subscale of the RBPC. This is considered higher than would be expected in a community sample and was primarily attributed to an increased score (>2) on the conduct disorder subscale. Another study (5) also noted an increase in the number siblings whose scores fell within the clinical range (26%), compared to a comparison group (3-6%) on a measure of conduct difficulties. In this study (5) there was also a significant difference between groups, with female siblings of children with DS scoring higher in conduct problems than siblings in a control group.

Several studies (8, 11, 12) considered the SEB adjustment of siblings of children with DS using measures other than the CBCL and RPBC. Studies reported no significant differences between siblings of children with DS and a control group (8, 11, 12). Interestingly however in one study (8) it was noted that parents believed their TD child to have more emotional problems, even when they identified few behaviours suggestive of such difficulties.

Additional findings included siblings of children with DS showing less internalising and externalising difficulties than siblings of children with ASC (11, 12, 28, 33) and siblings of children with DS reporting anxiety levels similar to what would be expected in a community sample (26).

Self-Concept. Three studies (6, 16, 28) considered the self-concept of siblings of children with DS. All three studies reported that there was no significant difference between siblings of TD children and siblings of children with DS. This finding followed the use of numerous measures, including the total competence subscale of the CBCL (6, 16), the Perceived Competence Scale for Children, The Pictorial Scale of Perceived Competence and Social Acceptance for young children (PCSA) (28) and the Self-Perception profile for Children (6). Where reported (6, 16), scores were considered to be within normal ranges.

Peer relationships. Three studies (6, 16, 28) considered the peer relationships and social competence of siblings. All three studies noted no significant difference between siblings of children with DS and siblings of TD children. A range of measures were used, including; PCSC and PCSA (28), the Social Competence subscale of the CBCL (16) and the SPPC (6).

Other findings included; no significant difference between sibling of children with ASC, siblings of children with DS and siblings of TD children on a measure of loneliness (16), with mean levels of loneliness lower than found in previous studies.

Adjustment Factors

Individual Factors

Sibling Age. Seven (1, 8, 9, 24, 26, 28, 32) studies explored the relationship between TD sibling age and sibling adjustment. Results were discordant; with one study (28) revealing that older siblings (> 12 years) of children with DS had significantly more internalising problems than younger siblings (<12 years), whilst older siblings of children with ASC had significantly more internalising problems and externalising problems. In one other study, older siblings of children with an ASC were also found to be more likely to score within a depressed range than younger siblings (9). Conversely, one study found younger siblings to experience borderline clinically significant difficulties, whilst older siblings scored within a 'normal range.' Other studies have found no association between sibling age and reported levels of anxiety (26) and psychosocial adjustment (1, 8, 24), across siblings of children with an ASC (1, 24, 26) and DS (8, 26).

Sibling Gender. Seventeen studies (4, 5, 6, 8, 9, 13, 14, 15, 16, 19, 21, 22, 23, 24, 26, 28, 32) included in the review considered the relationship between sibling gender and psychosocial adjustment. Four studies found male siblings of children with ASC to be at increased risk of adjustment difficulties (13, 14, 15, 32), whilst other studies noted female siblings of children with ASC (21) and DS (5,4) to experience more adjustment difficulties. Most studies (n = 9), however, failed to show a difference in outcomes according to gender, for both siblings of children with DS (8, 6, 16, 28, 26) and ASC (9, 16, 19, 24, 26, 28). Studies employing a qualitative method, also noted no gender difference in the themes generated (22, 23). Interestingly, however, whilst Gold (1993) (9) found no significant gender difference on a measure of depression, the correlates of depression did vary, leading to the suggestion that the factors which contribute to depression may differ by gender.

Birth Order. Nine studies (1, 5, 8, 9, 14, 16, 17, 25, 28) considered the correlation between birth order and sibling adjustment. Two studies reported a greater risk of adjustment difficulties (emotional and behavioural) in younger siblings (14, 25); whilst two studies (17,28) found that being an older sibling was associated with more risk of internalising and externalising behaviours. Gold (1993) (9) found a significant birth order and gender effect, with being the older sibling of a child with ASC, correlated with higher depression scores for sisters, but not brothers. Meanwhile, being younger than the child with ASC was correlated with higher CDI scores for girls but not boys. Six studies found that birth order did not impact on perceived competence (28) or SEB adjustment (1, 5, 8, 16), across siblings of children with ASC (1,16, 28) or DS (5, 8, 16, 28).

Socio-Economic Status (SES). Three studies considered the role of SES and siblings adjustment. All three studies (15, 17, 25) reported a significant correlation between the families' SES and sibling adjustment, with higher SES associated with better adjustment.

Other individual-level factors considered, include the number and type of coping strategies employed by TD siblings (29) and TD sibling knowledge of disability (29). No significant correlation with sibling adjustment was found for either factor.

Multiple Variables. Several studies have considered the combined impact of various individual and demographic factors. Using a hierarchical regression analyses, Hastings (2003a; 14) found that sibling variables (sibling sex, birth order, sibling age and gender match) explained a substantial (35%), although not significant, proportion of variance in siblings Total SDQ scores. In a different study, Mack and Reeve (2007) (17) created a risk scale composite in order to compare the cumulative effect of various demographic characteristics on sibling adjustment. A significant positive correlation was found between the risk scale, and siblings psychosocial adjustment, with the following factors associated with greater risk; being male, coming from a family with low SES, having only one sibling, and being older than the child with ASC. No significant correlations were found between the risk scale composite and the psychosocial adjustment of control siblings leading Macks and Reeve (2007) to suggest that when multiple demographic risk factors are present,

siblings of children with autism may find it more difficult to manage their situation, both emotionally and psychologically**.**

Family Factors

Sibling Relationship. Two studies (26, 12) have explored sibling relationships as a correlate of sibling adjustment. One study (12) found that a warm and close sibling relationship was associated, although did not mediate, positive outcomes for siblings of children with DS, but not for siblings of children with PDD. Meanwhile, Pollard et al., (2013) (26) revealed a significant correlation between negative sibling interchanges and sibling anxiety, in brothers and sisters of children with ASC and DS. Using a regression analysis, Pollard et al., (2013) considered the extent to which sibling relationship can predict anxiety. Results showed a significant effect for both groups, however subsequent analysis showed that when relationship quality was high, there were no significant difference in reported anxiety between children with ASC and DS. However when relationship quality was low, siblings of children with ASC had higher levels of anxiety than siblings of children with DS (26).

Family Size. Six studies considered the association between family size and the adjustment of siblings of children with ASC (5, 16, 17, 19, 26, 29) and DS (16, 26, 29). Two studies (16, 17) found a significant correlation between increased numbers of children in the family and positive sibling adjustment. Conversely, 4 studies (5, 19, 26, 29,) found no significant difference between sibling adjustment, and family size. In all four studies, comparisons were made between two-child and multi-child families.

Parental Wellbeing. Characteristics of parental wellbeing have been explored as correlates of sibling adjustment with the most frequently considered variable parental stress. Four studies (3, 11, 14, 15) found a significant positive correlation between siblings decreased psychosocial wellbeing and parental stress, for both siblings of children with ASC (11, 14, 15) and DS (3, 11). Despite finding positive correlations several studies have suggested that parental stress does not explain a significant proportion of variance in the adjustment of siblings of children with ASC (13, 14). However several studies have not explored the proportion of

variance explained by parental stress (3, 11) and one study (2) found no correlation between parenting stress and sibling wellbeing.

Sibling research has considered a range of other parental factors including parental depression and marital relationships. Studies found that higher levels of maternal depression significantly correlated and predicted SEB difficulties (4, 21) and anxiety (21) in siblings of children with ASC (21) and DS (4). This was despite parents, often scoring within the 'normal' range on a measure of depression (4, 21). A further study (12) found that parental distress (a combination of stress and depression) mediated the relationship between group membership (DS and PDD) and parent reports of both internalising and externalising behaviour in siblings.

Three studies (28, 4, 8) evaluated the association between marital satisfaction and adjustment outcomes. One study (28) found a strong positive correlation between marital satisfaction and the perceived competence of siblings of children with ASC, but not siblings of children with DS. This study did not consider behavioural adjustment. Two studies (8, 4) found no association between marital satisfaction and sibling adjustment.

Other reported parental factors have included a significant positive correlation between parental self-efficacy and the psychosocial wellbeing of siblings of children with ASC (15) and a positive correlation between maternal 'feelings of burden' (e.g. finding her caregiving responsibilities difficult to manage) and ASC siblings levels of depressive symptoms (9). Of these factors however, only parental satisfaction was found to hold predictive value (15).

In addition to the aforementioned parental factors, Gath and Gumley (1987) (8) found that a warm and cohesive home acted as a protective factor when the outcomes of siblings of children with DS and siblings of children with another disability were considered together.

Lastly, one study (33) explored the relationship between the perceptions of differential parent treatment and siblings internalising and externalising behaviour. It was noted that siblings of children with PDD perceived themselves as preferred, when their sibling was considered to have a high level of difficulty as reported by parents, whereas siblings of children with DS perceived their siblings as preferred

when their own level of difficulty was reported as high. Moreover, for siblings of children with PDD, the perception that they were preferred over their disabled sibling was predictive of adjustment difficulties. On the other hand, for siblings of children with DS the perception that their disabled sibling was preferred was associated with internalising difficulties.

Wider Societal Factors

Social Support. Five studies considered the impact of social support on the adjustment of children with ASC (2, 9, 14, 16, 33) and DS (16, 33). For siblings of children with an ASC a positive correlation was found between levels of social support and self-concept (2), and academic functioning (16), whilst a negative correlation was found between levels of social support and internalising and externalising difficulties (33). In addition, Gold (1993) (9) noted that siblings who reported having nobody to talk to about their sibling with an ASC scored significantly higher on a measure of depression.

For siblings of children with DS, whilst a negative correlation was found between levels of social support, and internalising and externalising difficulties (33), no significant correlation was found between high levels of social support and academic functioning (16). No studies considered social support and self-concept, in siblings of children with DS.

Contrary to the aforementioned findings, one study (16) found that whilst social support negatively correlated with loneliness, neither social support nor loneliness was significantly associated with target siblings (ASC & DS) behavioural or emotional adjustment. However it was noted that this finding might be due to the siblings of both children with ASC and DS in this study being considered well adjusted.

Two studies (13, 16) reported interactions between support and other factors. Firstly, Hastings (2003b) (13) found that formal support moderated the impact of symptom severity on the adjustment of siblings of children with an ASC. Specifically, when children were reported to have less severe autism symptoms, their siblings were less at risk for behavioural problems when the family also received high levels of formal support. Secondly, Kaminsky and Dewey (2002) (16) found

that siblings of children with ASC whose parents were support group attendees displayed fewer internalising, externalising and total adjustment problems on the CBCL, than siblings whose parents did not attend support groups. In addition Cebula (2012) found an association between parent's perceived helpfulness of support (formal & informal) and siblings self-reported SDQ scores.

Involvement in Interventions. Two studies (2, 13) considered the adjustment of siblings of children with ASC engaged in ABA. One study (2) found no significant difference between siblings SDQ scores or Self-Concept scores according to whether reference children with ASC were engaged in ABA or not. Meanwhile, another study (13) found siblings of children with ASC engaged in ABA to be significantly better adjusted, as recorded on the SDQ, than a normative sample. The authors note that this may be associated with the support associated with being engaged in ABA.

Behaviour of children with ASC and DS. Nine studies (1, 4, 8, 14, 18, 21, 23, 24, 31) considered the impact of the behaviour of reference siblings on the adjustment of target siblings. One study found a significant positive correlation between reported behaviour problems in the child with DS (8) and adjustment difficulties in the target sibling. A significant positive correlation was also found between the child with DS's level of competence, and TD sibling's positive behavioural adjustment (8). Several studies moved beyond a correlation, in order to consider the extent to which the reference sibling's behaviour predicted target siblings adjustment. Two studies (24, 31) found behaviour problems in the child with ASC (31, 24) to be a significant predictor of internalising (31, 24), externalising difficulties (24) and social problems (31) in TD sibling. However, one study (31) noted that the relationship between maladjustment in one sibling and maladjustment in another was mirrored across all sibling groups, including a control, and thus ASC symptom severity was not a moderator. Not all studies have found sibling's behaviour to explain a significant proportion of sibling adjustment (21, 14).

One study reported no relationship between the child with DS behaviour and the target sibling's adjustment (4).

Studies employing a qualitative methodology have noted that aggression is often reported as a high level concern by target siblings (18, 23, 1).

Reactions of Others. Several qualitative studies (20, 22, 23) noted that siblings expressed feelings of anger, embarrassment and anxiety, following the reactions of others including peers and strangers to their disabled sibling. It was also noted that siblings experience emotional discord due to wanting to stand up for their disabled sibling, but also wanting to fit in with their peers (23). Quantitative studies did not consider the relationships between peer reactions and sibling adjustment.

Family ASC. Research suggests that siblings of children with an ASC may be at increased risk of showing ASC characteristics, in a subclinical way, due to genetic susceptibility. This is referred to as the Broader Autism Phenotype (BAP) (31). Two studies (21, 24) found an association between BAP characteristics and depressive and anxiety symptoms in siblings, but only in the presence of other factors; either number of stressful life events (21) or the disabled sibling's behaviour difficulties (24). Thus siblings with high BAP scores who had brothers or sisters with more challenging behaviour or a high number of stressful life events were at greater risk of showing increased difficulties themselves. Petalas, Hastings, Nash, Hall, Joannidi & Dowey (2012b) suggests that this may support a diathesis-stress model. Lastly, one study (21) found that having a family history of ASC was associated with more depressive but not anxiety symptoms in siblings of children with ASC.

Household Responsibilities. Lastly several studies (3, 5, 6, 8) considered the association between involvement in household chores and caregiving, and sibling wellbeing. All four studies considered the wellbeing of siblings of children with DS only. Three studies noted an inverse correlation between domestic chores (3, 5) and caregiving (8), and adjustment difficulties in siblings. It should be noted however that in study 3 this relationship was reported by fathers only, not mothers. One study (6) found no significant correlation between caregiving or household chores, and the adjustment of TD siblings.

Discussion

The aim of the current review was to consider the SEB outcomes, and factors pertaining to these outcomes, of siblings of children with two specific disabilities; DS and ASC. A systematic procedure was used to identify as fully as possible the research literature in this field. 33 studies were identified and reviewed. The review found great disparity in findings, making it difficult to draw accurate conclusions. Nonetheless, the following points appear pertinent, although need to be treated with caution.

Siblings across both groups, ASC and DS, appear to experience few adjustment difficulties in regards to peer relationships and self-concept. That is sibling's scores fall within a 'normal' range, and do not differ significantly from a control group comparison. The results in terms of internalising and externalising behaviour are more varied. Some studies suggest that siblings of children with ASC experience more adjustment difficulties than control siblings or normative data. However, siblings are not automatically 'at risk' of clinically significant difficulties. Importantly, however, when the proportion of siblings experiencing difficulties is considered it appears that there may be a 'sub-group' who are more vulnerable. At times, the focus on mean scores may mask this. There is some evidence to suggest that where difficulties are experienced, they are more often of an internalising nature. Siblings of children with DS appear to experience fewer adjustment difficulties, although this is based on much less evidence.

Given these mixed findings and the presence of sub-groups of children who may be more vulnerable, it has been suggested that the presence of different risk and protective factors may contribute to the variability in sibling adjustment (Tomeny et al., 2012). Numerous factors have been considered. The association between demographic factors and sibling adjustment is unclear, with results presenting as mixed. However, for both siblings of children with ASC and DS, there is initial evidence that family factors, particularly parental wellbeing, correlate with sibling adjustment. There is less clarity about the extent to which these factors can predict sibling adjustment.

Although the association between individual demographic factors and sibling adjustment appears unclear, there was evidence to suggest that siblings' risk of

adjustment difficulties may increase in the presence of multiple demographic risk factors. As noted by Mack and Reeve (2007) this finding may contribute to explaining the mixed findings in the sibling literature, with some studies being characterised by siblings experiencing multiple demographic risk factors. This warrants further consideration. Several researchers have suggested that when considering sibling adjustment it may be of greater value to explore dynamic variables (e.g. coping), as opposed to static variables (e.g. gender), given the potential to change such factors (Giallo & Gavidia-Payne, 2006). However, developing a risk scale may be important in identifying siblings who may be more likely to experience difficulties. This seems particularly poignant given the suggestion that siblings as a whole group may not be 'at risk', but rather that a subgroup of siblings may experience increased difficulties. Given the reported association between SES and sibling adjustment, this is likely to need to be considered as one of the risk scale factors.

There was some recognition that factors may have a different impact on siblings according to disability status. For example, Fisman et al., (1996) found that for siblings of children with PDD, feeling that they were preferred over their disabled siblings was predictive of internalising difficulties. Conversely, for siblings of children with DS, the perception that their sibling was preferred, particularly over time, was associated with internalising difficulties. This highlights the need for future research to consider risk and protective factors in the context of specific disability groups.

The review highlighted that a range of different measurement instruments (e.g. CBCL, SDQ) have been used across sibling research. Previous researchers (Hodapp et al., 2005) have suggested that this may contribute to the mixed findings and lack of conclusive evidence so far. However this review highlighted that even when considering results according to the measure used, outcomes remain mixed.

Across study limitations. Although the use of different measures may not have been associated directly with outcomes, the use of different measures across studies remains a limitation. In particular, it makes across study comparisons difficult. Whilst the SDQ has been used on numerous occasions to consider the wellbeing of siblings of children with ASC it has yet to be used with siblings of

children with DS. In addition, across measures, there has been variation in the way in which data is analysed and reported. Again, this makes cross study comparisons more different. For example whilst some studies have considered mean scores of whole groups, others have focused on the proportion of siblings experiencing adjustment difficulties. As noted earlier these differing methods can lead to a different interpretation of findings, with the potential for mean scores to over shadow subgroups of siblings who may experience difficulties. It is important that where possible, further studies report both mean scores, and the proportion of siblings with adjustment difficulties. This may reveal important information about a potential subgroup of siblings with adjustment difficulties and help to highlight the factors that may be involved. The relatively small number of studies considering factors which impact on the adjustment of siblings, have considered a wide range of factors. Thus each factor has often been considered only a few times. This adds to the difficulty in establishing which factors may contribute to the adjustment of siblings.

Most studies rely on correlational analysis, with few studies exploring the predictive value of different variables. It has not been possible for studies to consider the cause and effect of the different variables. Few studies reported effect sizes, making it difficult to compare the magnitude of findings across studies. Nonetheless, in most incidences it was possible to calculate effect sizes from the information published within each paper. Inspection of effect sizes suggests that differences between groups are often relatively small, although again, vary.

Lastly, the review highlighted that siblings of children with DS have received considerably less research attention than siblings of children with ASC, with studies characterised by small sample sizes. Furthermore, there is a noticeable absence of qualitative research exploring the experiences of sibling of children with DS.

Limitations of included studies. In addition to limitations across included studies, there were also limitations within the studies included. Given the relatively small number of studies considering the adjustment of siblings, studies were not excluded on the basis of lower methodological quality. It is possible that this may have impacted on the reliability of the findings.

Firstly sample sizes were fairly small, particularly in studies considering the adjustment of siblings of children with DS. Several researchers commented on their

small sample size, with a reoccurring theme being the difficulty in participant recruitment due to the small number of potential participants within the population. As noted previously, no studies reported power estimations making it difficult to establish the extent to which studies had sufficient power to identify differences between groups. This is a criticism of almost all studies.

Secondly, a high proportion of studies recruited participants from support groups (e.g. NAS) or from samples recruited as part of a larger study. This may be considered a threat to internal validity in that participants may not represent the general population of children being studied. Families that feel that they have the time to participate may be those that are 'better' adjusted. Given the aforementioned finding that parental adjustment may be associated with sibling adjustment it is therefore possible that studies were characterised by the 'better' adjusted families and in turn siblings. Equally it is possible that families that volunteer may be families who are more open about their child's disabilities (Kaminsky & Dewey, 2002). This is poignant given the suggestion by Singer & Powers (1993) that 'openness about disability' may be associated with sibling wellbeing.

Thirdly, most studies were cross sectional studies, collecting correlational data. Whilst several studies considered the predicative value of variables, the lack of temporally varied data collection prevents any form of causation being established.

Fourthly, as noted earlier, it is important that research starts to consider more homogenous sibling groups, thus this review sought to focus on two specific sibling groups. However, the groups selected may not be as homogenous as anticipated. This seems particularly likely in the ASC sample, where some children with an ASC had a diagnosis of PDD, whilst others had a diagnosis of Asperger syndrome. Different variants of an ASC may present very different experiences for siblings. Similarly, no studies mentioned the health of siblings of children with DS, which may act as a confounding variable.

Lastly, most studies compromised external validity, as a result of lack of diversity within the samples, as they often represented only white middle class families. Stoneman (2005) notes that this is a concern of sibling research in general, with most studies needing to recruit samples which are more representative. This

would make results more generalizable. Most studies gave only limited consideration (i.e gender & SES) to how representativeness their sample was.

Overall, the quality of the included studies, may impact on the reliability of findings and contribute to the diverse findings reported.

Limitations of the review. Alongside limitations across, and within studies, there are several limitation of the review methodology which warrant consideration. Despite the systematic searching of literature, it is possible that due to the selection of search terms, not all relevant studies were included. Whilst additional hand searches were used and the generation of search terms an iterative process it is likely that some literature has been missed. Furthermore, it is possible that studies in which results were less significant or less conclusive have been excluded, due to the decision to exclude studies not published in a peer-reviewed journal. This raises the possibility of this review having been subjected to publication bias, which could lead to an inflation of the number of siblings with adjustment difficulties or increased wellbeing. Even within studies, it is possible that publication bias has impacted on findings, with several papers (e.g. Kaminsky & Dewey, 2002) noting that non-significant results had not been reported.

Further Research. The current review clearly shows that there is a need for research to continue focusing on the adjustment of siblings of children with DS and ASC. Specifically, there is a need for more research to consider the adjustment of siblings of children with DS, including qualitative studies. This would allow the lived experiences of siblings of children with DS to be better understood. The review also highlights the absence of consideration given to factors beyond the individual and family, which may influence the outcome of siblings. For example no consideration has been given to school factors, despite the fact that children spend a significant proportion of their time in school. This is contrary to Ecological Systems Theory, which notes the importance of considering all layers within which a child exists. Furthermore, whilst it is interesting to explore demographic variables (e.g. birth order, gender, age) and as noted earlier this may support the identification of 'at risk' siblings, it is important that dynamic factors are also given consideration due to the potential of such factors being utilised to bring about change (Giallo & Gavidia-Payne, 2006).

Conclusion

The current review considered the SEB adjustment of siblings of children with DS and ASC. Factors, which may be associated with sibling's wellbeing, were also explored. Results suggest that siblings of children with an ASC and DS may not automatically experience adjustment difficulties. However there may be a subgroup of siblings, particularly of children with ASC, who experience externalising and internalising difficulties. Family factors, particularly parental wellbeing, may correlate with sibling adjustment. A risk scale that explores the impact of multiple demographic factors may be valuable in identifying the siblings at greatest risk. Findings however, need to be treated with caution given the mixed results, and methodological challenges identified within the sibling literature.

This review highlights the need for research in the sibling domain to continue, including the need for further consideration of dynamic variables within the wider society, which may act as protective factors for siblings of children with disabilities.

Chapter 2: Empirical Paper

Exploring the role of school levels factors in the adjustment of siblings of children with disabilities

Word Count: 10611

A review of the literature exploring the wellbeing and adjustment of individuals growing up with a sibling with a disability reveals mixed findings (Green, 2013; Meadan, Stoner & Angell, 2009). Some researchers have reported increased levels of internalising and externalising difficulties among siblings of children with disabilities (e.g. Hastings, 2003a; Jones, Welsh, Glassmire & Tavegia, 2006; Rossiter & Sharpe, 2001), whereas others have reported no negative effect (e.g. Kaminsky & Dewey, 2002; Mates, 1990) or furthermore that siblings may be enriched by their experience of having a disabled sibling (Findler & Vardi, 2009; Macks & Reeve, 2007).

Defining Resilience

Various explanations have been offered for the disparate findings in the sibling literature. Of late researchers have increasingly drawn upon the resilience theory (e.g. Bellin & Rice, 2009; Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari, 1996). This theory posits that children who are exposed to similarly adverse circumstances are able to have divergent psychosocial outcomes, with some children demonstrating an ability to positively adapt (e.g. Luthar, Cicchetti & Becker, 2000; Masten, Best, Garmezy, 1990); that is, some children show greater resilience. Resilience has been defined in different ways by different investigators (e.g. Cicchetti & Garmezy, 1993; Masten et al., 1990; Luthar et al., 2000), but most often refers to the ability to 'bounce back' (Steward, Reid & Mangham, 1997; Garmezy, 1983; Place, Reynodls, Cousins & O'Neill, 2002), despite 'significant adversity' (Beardslee, Versage & Gladstone, 1998). For the purpose of the present paper resilience is operationalised as ''the attainment of desirable social outcomes and emotional adjustment, despite exposure to considerable risk" (Betancourt & Khan, 2008, p. 317).

Recently researchers have come to view resilience as a temporal process or 'dynamic state' rather than an individual characteristic (Rutter, 2006). More specifically, it has been suggested that resilience is the outcome of multiple interactions between risk and protective factors (Fergus & Zimmerman, 2005; Rutter, 2000; Masten & Obradovic, 2006; Werner & Smith, 1989). According to Masten (1994) a risk factor is any psychosocial adversity or event that would be considered a stressor to most people and that may hinder normal functioning. Meanwhile protective factors are defined as variables that modify or mitigate the impact of risk

exposure (Fraser & Galinsky, 1997). It has been argued that protective factors need to be understood in relation to the specific risk for which they are protective, and in terms of the specific behaviour which they protect against (Fraser & Galinsky, 1997; Rutter, 1987).

Several researchers have used an ecological framework to provide a context for thinking about risk and protective factors (Bellin, Bentley & Sawin, 2009; Bellin & Rice, 2009). According to this theory individuals are embedded in the centre of multiple ecological systems, which interact to influence development (Bronfenbrenner 1979, 1986, 1994; Fraser, Kirby & Smokowski, 2004). Therefore a child's resilience needs to be understood in the context of risk and protective factors across multiple interacting systems including the family, school and wider community (Riley & Masten, 2005).

It has been argued that embedding sibling research within a resilience and ecological framework "is a welcome shift from the dominant assumption that having a sibling with a disability is always going to be unfortunate" (Bachraz & Grace, 2009, p. 318). Importantly, the redefinition from assumed pathology to a focus on promoting wellbeing (Bachraz & Grace, 2009; Patterson, 2002) provides more scope for support and intervention (Giallo & Gavidia-Payne, 2006). In a similar vein, researchers have suggested that when exploring risk and protective factors the focus should be on 'dynamic variables', which are adaptable (e.g. coping style), as opposed to 'static variables' (e.g. gender), which may be viewed as fixed and thus arguably unchangeable (Giallo & Gavidia-Payne, 2006).

In summary, the theoretical framework outlined in this paper suggests that the interaction between risk and protective factors may contribute to the variation in outcomes reported within the sibling literature. 'Dynamic variables' across different ecological systems should be considered.

However, whilst a range of demographic (e.g. gender, age, birth order), individual (e.g. knowledge of disability) and family factors (e.g. maternal wellbeing, parents marital satisfaction) have been explored (e.g. Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari, 1996; Ross & Cuskelly, 2006; Wolf, Fisman, Ellison, Freeman, 1998), little consideration has been given to factors within 'wider society.'

School Level Factors

One area of 'wider society' that may be worthy of exploration, is the school context; this follows theoretical and empirical evidence, within domains other than the sibling literature, suggesting an association between a positive school experience and resilience in childhood (e.g. Dearden, 2004; Hojer & Johansson, 2012; Luthar et al., 2000; Luthar, 2006; Rutter & Maughan, 2002). Indeed, as stated by Masten, Herbers, Cutuli & Lafavor (2008), "The school context affords opportunity to facilitate resilience among children at risk for poor outcomes due to adversity exposure" (Masten et al., 2008, p. 78). Given the gaps in past research, the current study aimed to extend current research by exploring the association between wider society factors and sibling adjustment, with a specific focus on school level factors.

Three specific school levels factors can be identified from the resilience literature external to siblings of children with a disability, as worthy of consideration. These are 'sense of school belonging', 'teacher relationship' and 'peer satisfaction'.

Sense of School Belonging. It has long been recognised that a sense of belonging (SOB) is a fundamental human need (Frederickson & Baxter, 2009; Frederickson, Simmonds, Evans & Soulsby, 2007). Theoretically, this is supported by a number of perspectives, including Attachment theory (Bowlby, 1969, 1973, 1988), Maslow's Hierarchy of need (Maslow, 1943), and The 'Belongingness hypothesis' (Baumesister & Learly, 1995). In recent years the importance of a SOB in the school context has gained attention (e.g. Goodenow, 1993; McGraw, Moore, Fuller & Bates, 2008). This has become termed 'Sense of School Belonging' (SOSB) and defined by Goodenow (1993) as "sense of being accepted, valued, included and encouraged by others in the academic classroom setting and of feeling oneself to be an important part of the life and activity in the class" (Goodenow, 1993, p. 25).

Empirically SOSB has been associated with a range of outcomes, including social, emotional and behaviour (SEB) adjustment (e.g. Maddox & Prinz, 2003; Resnick et al. 1997; Murray & Greenberg, 2000; Waters, Cross & Shaw, 2010). More specifically, SOSB has been associated with adjustment and psychosocial outcomes, for 'at risk' groups. For instance a positive SOSB has been associated with decreased levels of depression and increased psychological wellbeing, in children who are refugees (Kia-Keating & Ellis, 2007) and children with a disability

(McMahon, Parnes, Keys & Viola, 2008). Longitudinal studies (e.g. Resnick et al., 1997) and intervention studies (e.g. Catalano, Haggerty, Oesterle, Fleimg & Hawkings, 2004) have provided additional support for SOSB as a protective factor. Given this empirical evidence, it seems reasonable to hypothesise that SOSB may also act as a protective factor for siblings of disabled children.

Teacher Relationship. Theoretically a positive teacher relationship is suggested to be important in that it provides children with a secure base from which they can explore and develop necessary social, emotional and behavioural skills (Birch & Ladd, 1997; Pianta, 1997). Empirical evidence, outwith the sibling literature, demonstrates an association between student-teacher relationships and the emotional and behavioural wellbeing of children. For example, an association has been found between a positive/effective student teacher relationship and positive social behaviour and peer relationships (Birch & Ladd, 1997; Howes, Hamilton & Matheson, 1994), classroom engagement (Furrer & Skinner, 2003) and a decrease in externalising and internalising difficulties (Hughes, Cavell & Jackson, 1999; Howes et al., 1994; Murray & Greenberg, 2000). Furthermore, evidence suggests that a supportive teacher relationship can act as a protective factor for children who may be at risk of poor psychosocial adjustment (e.g. Dent & Cameron, 2003; Hamre & Pianta, 2005). For instance, Brody, Dorsey, Forehand, and Armistead (2002) found that children living in disadvantaged homes were more likely to show resilience if they had a positive teacher relationship. Equally, positive teacher relationships were found to be important for children living in poverty (Dubois, Felner, Brand, Adan & Evans, 1992; Dubois, Felner, Meares & Krier, 1994). Given these findings, it may be that teacher relationship also plays a role in the adjustment of siblings of disabled children.

Peer Satisfaction. To date, a limited number of studies have considered peer difficulties in siblings of children with a disability. Studies have primarily adopted a qualitative method, for example, Mascha and Boucher (2006) conducted semi-structured interviews with 14 siblings (aged 11 to 18) of children with an ASC. Results showed that 72% of siblings reported feeling embarrassed when their sibling behaved inappropriately in front of their friends, or out in public. Equally, Barr and McLeod (2010) used thematic analysis to evaluate 676 contributions made by siblings to an Internet support group. Results showed that siblings felt that their

friends poorly understood their experience of living with a disabled brother or sister and at times were teased about their sibling. Other researchers have reported that siblings may feel reluctant to invite friends over to their house, due to worrying about their peers reactions to their sibling (Strohm, 2002; Dodd, 2004). In contrast Opperman and Alant (2003) reported that 63% of their sample of siblings of children with severe disabilities, felt respected by their peer group for their ability to cope with having a brother or sister with a disability. Equally Pit-ten and Loots (2000), noted "no indications of complications in peer relationships with having a sibling with a disability " (Pit-ten & Loots, 2000, p. 403).

Overall, the qualitative research suggests that siblings may experience altered peer interactions associated with their brothers or sisters additional needs. However it remains unclear how these difference are associated with sibling adjustment. Where qualitative studies have considered peer relationships, this has primarily been as an outcome (e.g. Kaminsky & Dewey, 2002; Hastings, 2003a) and thus the role of peer relationships as a protective factor remains unclear. Outside of the sibling literature, there is a wealth of research evidence, which suggests an association between peer relationships and children's SEB wellbeing (e.g. Hay, Payne & Chadwick, 2004; Dekovic, 1999). Moreover, numerous studies have identified the importance of peer relationships as a protective factor for children considered at risk (e.g. Bender & Losel, 1997; Criss, Pettit, Bates, Dodge & Lapp, 2002; Patterson, Cohn & Kao, 1989). For example Criss et al. (2002) found that positive peer relationships moderated the association between family adversity (ecological disadvantage, violent marital conflict and harsh discipline) and children's behavioural adjustment (e.g. externalising behaviour), so that high levels of family adversity were not associated with poor child adjustment, in the presence of high quality peer relationships. Indeed the authors concluded, "the results are consistent with the premise that peer relationships can help to reroute the adjustment trajectories of at-risk children in more adaptive directions" (Criss et al., 2002, p. 46). Satisfaction with peer relationships may therefore also have an important role to play in the adjustment of siblings of disabled children.

Methodological Challenges

In addition to the presence of different risk and protective factors, researchers have suggested that there are several methodological issues that may contribute to the previously contradictory findings (e.g. Giallo, Roberts, Emerson, Wood & Gavidia-Payne, 2014; Hodapp, Glidden & Kaiser, 2005). First, sibling research has often combined siblings of children with different disabilities (e.g. Down syndrome, autism and cerebral palsy) into one group (e.g. Giallo & Gavidia-Payne, 2006), despite the suggestion that outcomes for typically developing siblings may differ according to factors related to the specific diagnosis of the disabled sibling (Cuskelly, 2009; Fisman el al., 1999). Indeed, a small amount of literature has suggested that siblings of children with an ASD may experience more adjustment difficulties than siblings of children with DS (Fisman et al., 2000). It has therefore been suggested that there is a need for researchers to consider using more homogenous sibling groups (Hodapp et al., 2005). The second area of methodological concern is the use of different assessment tools, which make cross study comparisons difficult (Hodapp et al., 2005). In particular, numerous studies exploring the wellbeing of siblings of children with an ASC have utilised the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), whilst no studies have explored the wellbeing of siblings of children with DS using this measure. Lastly, previous research has been characterised by studies that include siblings spanning a wide age range. Giallo et al. (2014) suggest that such studies may lack the sensitivity require to identify developmental differences in adjustment, and thus contribute to the mixed findings in the literature. Hodapp et al. (2005) cover a range of other methodological challenges in their review.

Rationale and Aims of the Current Research

The literature suggests that there is a degree of variance in the psychosocial adjustment of siblings of children with a disability (e.g. Bangenholm & Gillberg, 1991; Giallo & Gavidia-Payne, 2006; Meadan et al., 2009), with some siblings showing resilience and appearing to thrive, while others are vulnerable to experiencing difficulties. As identified previously, various explanations for the mixed findings have been identified, including a range of methodological factors. These include the use of mixed assessment tools, the inclusion of siblings covering a

large age range, and heterogeneous groups of siblings (Cuskelly, 1999; Hodapp et al., 2005; Stoneman, 2005). The current thesis endeavours to address some of these limitations by utilising more stringent grouping methods and investigating the SEB adjustment of two specific sibling groups; siblings of children with an ASC or DS. Furthermore, the current study considers the adjustment of sibling's aged 7 to 11 only, thus a narrower age range than previous studies. Lastly, the study utilises an assessment tool, the Strengths and Difficulties Questionnaire (Goodman, 1997) yet to be used to explore the wellbeing of siblings of children with DS.

Alongside the aforementioned methodological challenges, theoretically there is reason to argue that risk and protective factors, across different interacting systems, may be associated with the psychosocial wellbeing of siblings of disabled children. Empirical evidence has started to explore demographic, individual and family factors, however to date, despite theoretical relevance, limited consideration has been given to factors in the wider society, including school factors. The second aim of the present study is therefore to expand the current understanding of sibling adjustment, by exploring risk and protective factors at the school levels. To address this aim, the current study explores the association between three school levels factors; Sense of School Belonging (SOSB), Teacher Relationship and Peer satisfaction, and sibling adjustment using a cross sectional survey design. These school level factors have been identified from literature exploring the wellbeing of other 'at risk' groups (e.g., the adjustment of children living in poverty; Dubois, Eelner, Brand, Adan & Evans, 1992). In the case of SOSB, the belonging scale was used, having been used to measure this construct in previous studies (Frederickson, Simmonds, Evans and Soulsby, 2007). In order to explore social dissatisfaction, the loneliness and social dissatisfaction questionnaire revised by Cassidy & Asher (1992) was used. This measures is reported to explore children feelings of loneliness and social adequacy, and in previous studies has been used as a measure of peer satisfaction and social dissatisfaction (De Roiste, 1998). Likewise, the Teacher support scale of the School Success Profile was used, having been used in previous studies as measure of teacher relationships (Bowen & Chapman, 1996). As in previous research (e.g., Petalas, 2009b) the strength and difficulties questionnaire was used as a measure of sibling SEB wellbeing.

In summary, the overall aim of the current thesis was to expand explanations of sibling adjustment, with a focus on siblings aged 7 to 11 of children with DS or ASD, by identifying risk and protective factors at the school level. Such variables may have important implications for intervention work, particularly given the dynamic nature of the school factors explored.

Research Questions

1: What are the Social, Emotional and Behavioural outcomes for siblings aged 7 to 11, of children with ASC, DS and siblings of TD children, as reported by parents?

2: What is the relationship between school level factors (e.g. SOSB, Teacher Relationship and social dissatisfaction as reported by siblings, and sibling, aged 7 to 11, adjustment (as reported by parents)?

3: Do school level factors, as reported by siblings, explain a significant proportion of variance in the adjustment of siblings (as reported by parents) aged 7 to 11?

4: Does the inclusion of school level factors add to the proportion of variance explained in sibling adjustment scores?

In addition, the association between family and individual factors, and sibling adjustment will be considered, allowing for a model of sibling adjustment to be explored.

Hypotheses

1: Siblings of children with ASC and DS will show more adjustment difficulties than siblings of TD children.

2: A positive SOSB, and positive peer and teacher relationships, will be associated with positive sibling adjustment.

3: School level factors will explain a significant proportion of sibling adjustment.

4: A higher proportion of sibling adjustment will be explained following the inclusion of school level factors to a model of sibling adjustment.

Method

Design

A cross sectional survey research design was used to investigate the psychosocial adjustment of siblings of children with an ASD and DS. All data was collected at one time point. Power was calculated using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007), which calculates, power using Cohen's d. The effect size (ES) used for this calculation was taken as an average of Cohen's d effect sizes from the literature review presented in chapter one, which gave an average Cohen's d effect size of 0.55. G*Power suggested that at a significance level of 0.5 between 77 and 111 participants were required depending on the statistical test used.

Participants

Participants were 204 parent and sibling pairs. This included 72 typically developing (TD) siblings (31 boys, 41 girls) of children with ASC, 76 TD siblings (46 boys, 30 girls) of children with DS and 56 TD siblings (24 boys, 32 girls) of children with no disability, which formed a control group. Hereafter the siblings whose adjustment is being investigated are referred to as "target siblings", while their brother or sister with a disability are referred to as "reference children" Sibling pairs (e.g. reference and target siblings) which included a child with either an ASC or DS, are referred to as the 'focus group,' whereas groups in which both siblings are TD (i.e. no disability present) are known as the control group.

To be included in the study, siblings and parents were required to meet the inclusion criteria shown in Table 4. In families where more than one TD sibling met the study's inclusion criteria, the sibling closest in age to the disabled child participated. In families where more than one parent was eligible for inclusion, families were asked to select which parent would participate. In most incidences (95%), this resulted in mothers completing the questionnaires.

All participating parents were the biological parent of both the target and reference sibling. Parents were asked to confirm that neither target siblings nor themselves had a known illness or disability. Parents were also asked to confirm the

diagnosis of the reference sibling. Demographic characteristics for participating parents are presented in Table 5.

All target and reference siblings were living at home full time, and attended a day school. Reference siblings did not participate directly in the study. Further characteristics of target and reference siblings are described in Table 6.

Table 4

Participant Inclusion and Exclusion Criteria

Respondent	**Focus Group**	**Control Group**
Sibling	Aged 7 to 11 years.	Aged 7 to 11years.
	Living at home.	Living at home.
	Able to read and understand English.	Able to read and understand English.
	No known disability or illness.	No known disability or illness.
	Sibling with an ASC or DS, aged 7 to 16 years who lives at home full time.	Typically developing sibling aged 7 to 16 years who lives at home full time.
Parents	No known disability or illness.	No known disability or illness.
	Able to read and understand English.	Able to read and understand English.

Table 5

Parent Demographics

Demographic Variable	Parent of children with DS	Parent of children with ASD	Parents of children without a disability Control	Total
	***N*=76**	***N*=72**	***N*=56**	***N*=204**
Parent Gender/Relationship to disabled sibling, *n* (%)				
Female (Mother)	68 (89.5)	70 (97.2)	55 (98.2)	193 (94.6)
Male (Father)	8 (10.5)	2 (2.8)	1 (1.8)	11 (5.4)
Parents Age, *n* (%)				
18 to 24 years	0 (-)	2 (2.8)	0 (-)	2 (1)
25 to 34 years	13 (17.1)	4 (5.6)	11 (19.6)	28 (13.6)
35 to 44 years	38 (50.0)	60 (83.3)	37 (66.1)	135 (66.1)
45 to 54 years	25 (32.9)	6 (8.3)	6 (10.7)	37 (18.1)
Missing	0 (-)	0 (-)	2 (3.6)	2 (1.4)
Parents Age in Years, M (SD)	41.2 (30)	39.3 (37)	38.6 (36.2)	39.9 (37.1)
Marital Status, *n* (%)				
Married/with Partner	57 (75.0)	59 (81.9)	42 (75)	158 (77.5)
Separated./Divorced	13 (17.1)	11 (15.3)	9 (16)	33 (16.2)
Widowed	0 (-)	0 (-)	1 (1.8)	1 (.5)
Single	6 (7.9)	0 (-)	0 (-)	6 (2.9)
Missing	0 (-)	2 (2.8)	4 (7.2)	6 (2.9)
Highest Level of Education, *n* (%)				
School Level	32 (42.1)	15 (20.8)	6 (10.7)	53 (26)
Work based	18 (23.7)	15 (20.8)	24 (42.8)	57 (27.9)
Degree	15 (19.7)	30 (41.7)	17 (30.4)	62 (30.4)
Post graduate	9 (11.8)	2 (2.8)	4 (7.2)	15 (7.4)
PHD/ Doctorate	2 (2.6)	10 (13.9)	2 (3.6)	14 (6.8)
Missing	0 (-)	0 (1)	3 (5.4)	3 (1.5)

Employment Status, *n* (%)				
Employed 1-39 hours	61 (80.3)	57 (79.2)	32 (57.1)	150 (73.5)
Employed 40+ hours	1 (1.3)	2 (2.8)	10 (17.9)	13 (6.4)
Unemployed	13 (17.1)	9 (12.5)	10 (18.9)	32 (15.7)
Other	1 (1.3)	4 (5.6)	0 (-)	5 (2.5)
Missing	0 (-)	0 (-)	4 (7.1)	4 (1.9)
Household Income, *n* (%)				
Less than £15000	6 (7.9)	5 (6.9)	0 (-)	11 (5.4)
£15000-£29999	23 (30.1)	32 (44.4)	20 (35.7)	75 (36.8)
£30000- £49999	26 (34.2)	24 (33.4)	22 (39.3)	72 (35.3)
£50000 and above	14 (18.4)	9 (12.4)	8 (14.3)	31 (15.2)
Missing	7 (9.2)	2 (2.9)	6 (10.7)	15 (7.3)

Note. ASD =Autistic Spectrum Disorder; DS = Down syndrome, *N*= number of participants

Table 6

Disabled Child and TD Sibling Demographics

Demographic Variable	**Sibling of children with DS**	**Sibling of children with ASD**	**No disability Control**	**Total**
	***N*=76**	***N*=71**	***N*=57**	***N*=204**
Gender of disabled child, *n* (%)				
Male	51 (67.1)	54 (75)	29 (51.8)	134 (65.7)
Female	25 (32.9)	18 (25)	24 (42.9)	67 (32.8)
Missing	0 (-)	0 (-)	3 (5.4)	3 (1.5)
Age disabled child (years), M (SD)	10.8 (2.8)	10.2 (2.6)	9.9 (2.7)	10.2 (2.7)
Age range of disabled child (years)	7 to 16	7 to 16	7 to 16	7 to 16
Severity of child's disability, *n* (%)				
Mild	11 (14.5)	14 (19.4)	-	25 (17)
Moderate	47 (61.8)	33 (45.8)	-	80 (53.8)
Severe	18 (23.7)	20 (27.8)	-	38 (25.8)
Very Severe	0 (-)	5 (6.9)	-	5 (3.4)
Gender of TD child, *n* (%)				
Male	46 (60.5)	31 (43.1)	24 (42.9)	100 (49)
Female	30 (39.5)	41 (56.9)	33 (57.1)	104 (51)
Age of TD child (years), M (SD)	9.1 (1.5)	9.3 (1.5)	9.0 (1.4)	9.1 (1.5)
Age range of TD child (years)	7- 11	7-11	7 -11	7-11
TD Child's position in Family, *n* (%)				
1st Child	24 (31.6)	24 (33.3)	18 (32.1)	66 (32.4)
2nd Child	34 (44.7)	34 (47.2)	26 (46.4)	95 (46.1)
3rd Child	15 (19.7)	11 (15.3)	6 (10.7)	31 (15.6)
4th Child	3 (3.9)	2 (2.8)	2 (3.6)	7 (3.4)
5th Child	0 (-)	1 (1.4)	2 (3.6)	1 (.5)
Missing	0 (-)	0 (-)	4 (7.1)	4 (2.0)
School, *n* (%)				
Same School	23 (30.3)	10 (13.9)	-	33 (22.4)
Different School	49 (64.5)	55 (76.4)	-	104 (70.8)
Inclusion unit as part of same school	4 (5.3)	6 (8.3)	-	10 (6.8)

Sibling Support group, *n* (%)				
Current – Yes	10 (13.2)	14 (19.4)	-	24 (16.3)
Current – No	66 (86.8)	58 (80.6)	-	124 (83.7)
Previously – Yes	15 (19.7)	8 (11.1)	-	23 (15.6)
Previously - No	61 (80.3)	64 (88.9)	-	125 (84.4)

Note. ASD =Autistic Spectrum Disorder; DS = Down syndrome, *N*= number of participants

Participants from the two focus groups (ASC/DS) were recruited from Special Needs schools and social or interest groups (e.g. NAS, Down's syndrome society) that support families and children with ASC and/or DS. Participants for the control group were recruited from local primary schools and interest groups (e.g. Brownies and Scouts).

Measures

Parents and siblings both completed a questionnaire booklet. The questionnaires completed by participants are shown below in Table 7, and this is followed by a description of each measure, including details of psychometric properties.

Table 7

Measures completed by Parents and Siblings

Respondent	Measure	Author(s)
Parents	Demographic Questionnaire	Compiled for present study
	Strengths and Difficulties Questionnaire	Goodman, 1997
	Depression, Anxiety and Stress Scale (DASS	Lovibond & Lovibond, 1995
	The UCLA Loneliness Scale	Russell, 1996
	Differential Parenting Index	Davis & Gavidia-Payne (unpublished – see appendix g)
	Knowledge of Disability Scale	Davis & Gavidia –Payne (unpublished – see appendix h)
Siblings	Loneliness and Social Dissatisfaction Questionnaire	Cassidy & Asher, 1992
	The Belonging Scale	Frederickson, Simmonds, Evans and Soulsby, 2007
	School Success Profile Dimensions	Bowen and Richman (2005)
	Differential Parenting Index	Davis & Gavidia-Payne (unpublished – see appendix g)
	Knowledge of Disability Scale	Davis & Gavidia –Payne (unpublished- see appendix h)

Parent-Completed Measures

Demographic variables. A demographic questionnaire compiled for the purpose of this study was completed by parents and was used to gather information about family characteristics (family income), the target sibling (age, position in family, gender), the reference sibling (age, gender, disability) and the participating parent (employment status, marital status). Most questions were presented in the form of multiple choice, with the option to provide an alternative answer.

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). Parents completed the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) as a measure of the target sibling's adjustment. The SDQ is a 24-item measure, which asks parents to score items from three options: *Not true (=0), somewhat true (=1) and certainly true (=2)*. Responses are provided over five subscales, four of which report difficulties: Conduct Problems, Emotional Symptoms, Hyperactivity and Peer Relationships. The 4 subscales can be summed together to generate a Total Difficulties score. Higher Scores are considered indicative of greater adjustment difficulties. The fifth scale measures pro-social behaviour. The SDQ has been developed for use with 4 – 16 year olds, with normative data available from a large-scale study, including British school children (Meltzer, Gatward, Goodman & Ford, 2000). Cut off scores, indicating clinical levels of difficulty have been provided by Goodman (1997). The SDQ has been found to have good internal reliability, with Cronbachs > .70 (Goodman, Meltzer & Bailey, 1998). In the current study Cronbach's alpha ranged from .74 to .80 across subscales.

Depression, Anxiety and Stress Scales (DASS) (Lovibond & Lovibond, 1995). The DASS is a 21 item self-report questionnaire measuring depression, anxiety and stress, with the total score considered to provide a general index of psychological adjustment (Crawford & Henry, 2003). In the current study, the measure was used to consider parental wellbeing. The questionnaire asks participants to rate questions according to how they felt during the previous week on a scale with responses scored from 0 ("*Did not apply to me at all*") to 3 ("*Applied to me very much, or most of the time*"). Cut-off scores for clinical significance have

been proposed for each subscale, as well as the total score. The measure has been reported to have good internal consistency, with Cronbach's alpha ranging from .84 to .91 when used with a non-clinical sample (Antony, Bieling, Cox, Enns, & Swinson, 1998). In the current study Cronbach's alpha was comparable ranging from .72 for stress to .81 for total adjustment.

The UCLA Loneliness Scale - Version 3 (Russell, 1996). The UCLA Loneliness Scale (Version 3) is a simplified version of the UCLA Loneliness scale (Russell, 1996). In the present study, this measure was used to assess parent's feelings of loneliness and social isolation. The UCLA is made up of 20 questions. Items are scored from 1 to 4 over four options: "*I often feel this way," "I sometimes feel this way," "I rarely feel this way*" and "*I never feel this way*." 11 items are negatively phrased and thus were reverse scored during analysis. The UCLA Loneliness Scale (Version 3) has been found to be very reliable, with coefficient alpha ranging from .89 to .94 (Russell, 1996). In the present study Cronbach's alpha was >.70, thus showing acceptable levels of reliability.

Differential Parenting Index – Parent (Davis & Gavidia-Payne, 2014). Following permission from the authors (Davis & Gavidia-Payne – see appendix g) the Differential Parenting Index was used to assess the extent to which parents feel they treat target and reference siblings equally (e.g. 'In comparison to your child with a disability, how do you feel you treat your child without a disability?). Parents were also asked to evaluate target siblings satisfaction with parental treatment (e.g. 'Please rate how you believe your TD child feels about this treatment'?). Responses for both questions were rated on a 5 point likert scale from *1= 'Exactly the same'* to *5 = 'Very different.'* No previous reliability and validity information is available for this measure.

The Knowledge of Disability Scale – Parent (Davis & Gavidia-Payne, 2014). Following permission from the authors (Davis & Gavidia-Payne- see appendix h) the Knowledge of Disability scale was used to assess parent's beliefs about target sibling's knowledge of disability. Parents were asked to respond on an analogue scale, ranging from 0 to 10, with 0 suggesting siblings to have little understanding and 10 suggesting that sibling know the most that he/she can. No previous reliability and validity information is available for this measure.

Sibling-Completed Measures

The Loneliness and Social Dissatisfaction Questionnaire for Children (Cassidy & Asher, 1992). The Loneliness and Social Dissatisfaction questionnaire was completed by siblings and was used to explore siblings' perceptions of loneliness and dissatisfaction with peer relations (Cassidy & Asher, 1992). The inventory consists of 24 questions, 8 of which are filler items; designed to make the child feel more relaxed (e.g. I like to paint and draw). Responses are rated on a 3-point scale according to how much each statement is considered a true description (e.g. *Yes, No, Sometimes*), with seven items reverse scored (Items 6, 9, 12, 18, 20, 21 and 24). High scores indicate greater loneliness and social dissatisfaction. The measure has been standardized for use on children aged 5-12 years. Studies have suggested that the questionnaire has good internal reliability, with a Cronbach's alpha coefficient of .79 (Cassidy & Asher, 1992). Reliability was comparable in the present study (Cronbach's $\alpha = 0.74$).

The Belonging Scale (Frederickson et al., 2007). The Belonging Scale is an adapted version of the Psychological Sense of School Membership (PSSM Scale; Goodenow, 1993), which has been reduced from 18 to 12 items, 'anglicised' and simplified for children as young as 8 (Frederickson et al., 2007). It is designed to assess the extent to which a child feels a sense of belonging to their school. The measure asks children to rate how true they feel eight statements are for them. Three options scored 1 to 3 are provided: '*No not true,' 'Not sure'* and '*Yes true*.' One-third of the items are phrased in a negative direction and thus subsequently reverse scored. Typically, a high score is considered indicative of a high SOSB.

School Success Profile (Bowen & Richman, 2005). The 8-item teacher support subscale from the school success profile (SSP) was used to explore sibling's perspective of teacher support. The SSP was developed based upon Bronfenbrenner's ecological model and research from within a resilience framework (Bowen, Rose & Bowen, 2005). The questionnaire asks respondents to score each of the 8 items on a scale of 1 to 4, with *1 = Strongly disagree* and *4 = strongly agree*. A high score is reported to be indicative of a positive teacher relationship. The measure has been

shown to have good reliability (Cronbach's α = 0.89), which was echoed in the present study (Cronbach's α = 0.76).

Differential Parenting Index – Sibling (Davis & Gavidia-Payne, 2014). See above – 'Differential Parenting Index – Parents'. Target Siblings were asked to evaluate the perceived level of differential treatment between themselves and their disabled sibling (e.g. In comparison to your brother or sister with a disability, how do you feel your parents treat you?') and their satisfaction with the treatment (e.g. Please rate how you feel about this?).

The Knowledge of Disability Scale – Sibling (Davis & Gavidia-Payne, 2014). See above – 'The Knowledge of Disability Scale – Parents'. Siblings were asked to respond on an analogue scale the extent to which they feel they understand their brother or sister's disability.

Data collection procedure

Support services, schools and charities (e.g. NAS and Down's Syndrome Association) were sent an initial letter of introduction, which briefly described the research aims and requirements of the study (see Appendix J). The letter asked services to support the process of participant recruitment by sending out information packs to families who may meet the studies inclusion criteria.

Included in the information pack was a detailed description of the study (Appendix K, L, M) and consent forms for siblings and parents. Families who wished to participate were asked to return consent forms in a prepaid envelope. Families were also asked to indicate if they would like to complete paper versions of the questionnaire, or an on-line version. Contact details for the researcher were provided. Although reference siblings did not participate directly, families were encouraged to discuss the study with reference siblings where they felt this to be appropriate.

Following the receipt of a signed consent form from both parents and the target sibling, participants were sent either a paper questionnaire or details for an online version, according to their preference. Both questionnaire booklets (parent and

siblings) took approximately 30 minutes to complete. Completed paper questionnaires were returned to the researcher in a supplied self-addressed envelope.

It is unknown how many information packs were sent out by services. However 306 families went on to contact the researcher after receiving an information pack. 26% of participants chose to complete questionnaire booklets online, with the remaining participants selecting for paper booklets to be sent. 66% of questionnaires sent (either on-line or via the post) were returned completed.

For all groups once a completed questionnaire had been received, both parents and children were sent debriefing information (Appendix N,O,P). Siblings were also sent a certificate to thank them for their participation.

Ethics

Ethical approval for the current study was obtained from the University of Southampton's ethics committee (see Appendix E and Q). Participants (parents and siblings) were provided with detailed information about the study allowing participants to give informed consent; this included being provided with contact details for the researcher should participants have any questions. While there were no anticipated risks for participants it was acknowledged that for some parents and siblings talking about their disabled child/ sibling might elicit feelings of distress or anxiety. Participants were reminded of their right to withdraw from the study at any point, without giving reason and without their rights being affected in any way. Participants were also reminded that they could miss any questions, which they felt uncomfortable answering – with the exception of annual income no parents or sibling missed any questions. See Appendix Q for a full ethics application.
Where necessary, permission to use questionnaires was obtained from authors.

Results

Data Preparation

The data was analysed using the Statistical Package for the Social Science (SPSS) Version 21. The primary researcher entered all data, with 20% double entered in order to check for errors. Given that the error rate was < 2%, the data was considered to have been reliably entered. The data from each questionnaire was screened to check for missing data. This resulted in the data from one participant being removed from the data set, due to > 50% of values missing. With the exception of some demographic information (primarily SES) no other missing data was found, and thus no other cases were excluded.

Preliminary analysis was carried out on the data from each measure to screen for violations to the assumptions for parametric procedures. The data was considered within the limits of a normal distribution if the z score of skewness and kurtosis, did not exceed +/- 3.29, reflecting the use of a medium-sized sample (Hae-young, 2013). Box plots were also inspected. In cases where the homogeneity of variance assumption was violated, the result of the Levene test were interpreted in conjunction with the variance ratio (Hartley's F) and compared to the critical value for the sample size (Field, 2009). Following recommendation by Field (2009) the outcome scores of each measure were converted to z-scores in order to detect for outliers. Scores of +/- 2.5 were considered an outlier.

Plan of Statistical Analysis

First, mean scores on all of the SDQ subscales, including total difficulties, were compared across the three sibling groups (ASC, DS and Control) using an Analysis of Variance (ANOVA). Siblings' scores on the SDQ were categorised into Normal, Borderline and Abnormal, following recommendations made by Goodman (1997). Previous research suggests that approximately 10% of children will score in the Borderline and Abnormal range of the SDQ, with 80% scoring within the 'normal' range (Goodman, 1997). As Goodman (1997) did not adjust ranges according to gender differences, independent samples t-tests were conducted for each

of the SDQ subscales and the Total Difficulties score, to ensure there were no sex differences. No differences were found.

Second, the outcomes on three school variables, (SOSB, social dissatisfaction and teacher relationship), was compared across sibling groups, using an ANOVA. The association between the three school factors and siblings social, emotional and behavioural outcomes (as measured by the SDQ) was then explored separately for each of the three groups, using Spearman's rank order correlations or Pearson's Correlation Coefficients. Stage 2 was repeated three times, replacing school factors with previously explored sibling factors and family factors.

Finally, regression analysis was carried out in order to establish the proportion of variance explained by school factors. The intention was to then enter a combination of predictor variables (e.g., individual, family and school factors) into a multiple regression in order to explore the explanatory value added by school factors. However this was not possible, due to insufficient predictor variables at the school level.

Throughout analysis, effect sizes were calculated using Pearson's correlation coefficient, with the magnitude evaluated following guidelines provided by Cohen (1988): r = 0.10 = small effect, r = 0.30 = medium effect, r = 0.50 = large effect. To control for type 1 error following multiple comparisons, the significance level was set at $\leq .01$ for all analyses.

Descriptive Statistics

A series of chi-square tests were performed in order to assess whether the three groups (DS, ASC, Control) differed on demographic variables (gender, position in family, children in family, disability severity, previous and current sibling support group attendance, household income, parental marital status and employment status.) No significant differences were found between groups, with all ps >.01.

Preliminary analyses of Siblings Adjustment Scores

Tests of normality on the SDQ revealed a large positive skew for Conduct Problems (z skewness = 0.11 to 6.99; z kurtosis = 0.53 to 4.05) and Peer Problems (z

skewness = 2.71 to 6.59; z kurtosis = 0.36 to 8.52) indicating a greater number of low scores relative to high scores. This violation was found irrespective of whether the sample was considered as a whole or in individual subgroups (ASC, DS, Control). Following this violation to the assumption of normality, the data from the Conduct Problems and Peer Problems subscale was subject to a Lg10 transformation (1 was added to all transformations to allow for scores of 0), with scores subsequently normally distributed (skewness: z = 0.042 to 2.84; Kurtosis: z = 0.00 to 1.53). The Levene's test was non-significant. It was therefore assumed that linearity and homoscedasticity were satisfactory for subsequent analysis. Assumptions of normality were met for the SDQ Emotional symptoms subscale, SDQ Prosocial subscale, SDQ hyperactive subscale and the SDQ total score. Following the transformation, based on the recommendation by Field (2009) the outcome scores of all SDQ subscales were converted to z-score values in order to detect outliers. No outliers were identified.

Sibling's Social, Emotional, Behavioural Adjustment

The Mean and SD SDQ scores for each of the sibling groups are shown in Table 8.

Table 8

Mean and SD SDQ scores of siblings in two disability groups, control group and normative sample

SDQ Scale	ASC	DS	Control	Normative
Emotional Symptoms	3.61 (2.48)	2.26 (1.97)	2.07 (1.78)	1.6 (1.7)
Conduct Problems	2.62 (2.35)	2.02 (1.82)	2.05 (1.24)	1.9 (2.0)
Hyperactivity	3.93 (2.21)	3.21 (1.83)	2.85 (2.10)	3.6 (2.7)
Peer Problems	2.93 (2.38)	2.89 (1.92)	1.62 (1.52)	1.4 (1.7)
Total Difficulties	13.09 (7.47)	10.44 (5.68)	8.60 (4.04)	8.6 (1.6)
Prosocial Behaviour	7.75 (1.86)	7.90 (1.86)	8.25 (1.49)	8.6 (5.7)

Note. Although the data for two of the SDQ subscales was subject to a transformation, the untransformed mean scores are reported allowing for comparison with previous studies. This followed checks to ensure that the same pattern of findings was found irrespective of the transformation (Field, 2009).

An ANOVA revealed a statistically significant difference between groups in the SDQ Emotional Symptoms domain, ($F[2, 201] = 10.69$, $p<.001$), Peer Problems Domain ($F[2, 201] = 13.36$, $p<.001$), Hyperactivity ($F[2,201]= 4.68$, $p= .010$) and Total Difficulties Score ($F[2,201] = 9.06$, $p<.001$). No significant differences were found between groups in the Prosocial subscale ($F[2,201] = 1.28$, $p>.05$) and Conduct Problems subscale ($F[2,201] = 1.133$, $p>.05$).

Post hoc contrasts, using Hochberg's GT2 (due to unequal sample sizes), were carried out. Results showed that siblings of children with ASC, were reported by parents, to have significantly higher levels of emotional symptoms, compared to siblings of children with DS ($p<.001$, $r = .29$) and siblings of children with no disability ($p<.001$, $r= 0.33$). No significant difference was found between siblings of children with DS and the control group ($p>.05$).

On the Peer Problems subscale a significant difference was found between siblings of children with ASC and the control group (p <.001, r = .32) and between siblings of children with DS and the control group (p <.001, r =.31). Parents of children with ASC and DS reported that their TD child had significantly higher levels of peer problems compared to reports for control children. No difference was found between the levels of peer problems between siblings of children with DS and ASC (p>.05).

Post hoc analysis revealed siblings of children with ASC, to have significantly higher levels of hyperactive behaviour when compared to control siblings (p=.01, r= 0.24), but not siblings of children with DS (p>.05). Siblings of children with DS did not differ from the control group (p>.05) or from siblings of children with ASC (p>.05).

Lastly, on the SDQ Total Difficulties score, siblings of children with ASC were reported as having significantly more overall difficulties than control siblings (p<.001, r= .35), but not siblings of children with DS (p>.01). No significant difference was found between siblings of children with DS and a control group (p>0.05).

According to the bandings provided by Goodman (1997) siblings of children with DS were found to have borderline clinically significant peer difficulties (M=2.89, SD=1.92). Siblings of children with an ASC were found to have borderline clinically significant emotional symptoms (M = 3.61, SD=2.49), borderline conduct problems (M =2.62, SD=2.36) and borderline peer problems (M = 2.93, SD=2.38). Siblings of TD children were found to score within a 'normal' range on all subscales.

Proportion of Siblings in Clinical and Non-Clinical Groups on SDQ

Z tests were conducted in order to investigate if the proportion of siblings in the clinical range, for each subscale, was significantly different between groups. Results showed that significantly more siblings of children with ASD scored in the abnormal range on the Emotional Symptoms subscale, compared to siblings of children with DS (z=2.52, p=0.01) and control siblings (z=2.85, p=.004). No other significant differences were found. See Table 9 for full details of the proportion of siblings within clinical ranges, by each SDQ subscale and group.

Table 9

Sibling scores by Group and Normal, Borderline and Abnormal range over SDQ subscales.

SDQ Scale	Group			
	ASC ***N*=72**	**DS** ***N*=76**	**Control** ***N*=56**	**Normative Data**
	***N* (%)**			
Emotional Symptoms				
Normal (0-3)	57 % (*n*=41)	75% (*n*=57)	82%(*n*=46)	81%
Borderline (4)	11% (*n*=8)	11 % (*n*=8)	11%(*n*=6)	8.3%
Abnormal (5-10)	31% (*n*=23)	14 % (*n*=11)	7% (*n*=4)	10.6%
Conduct Problems				
Normal (0-2)	61% (*n*=44)	71% (*n*=54)	71% (*n*=40)	75.3%
Borderline (3)	12 % (*n*=9)	9% (*n*=7)	18% (*n*=10)	11.6%
Abnormal (4-10)	26 % (*n*=19)	20% (*n*=15)	11% (*n*=6)	13.1%
Hyperactivity				
Normal (0-5)	82% (*n*=59)	90% (*n*=68)	89% (*n*=50)	76.2%
Borderline (6)	7% (*n*=5)	4% (*n*=3)	2% (*n*=1)	7.7%
Abnormal (7-10)	11% (*n*=8)	7% (*n*=5)	9% (*n*=5	16%
Peer Problems				
Normal (0-2)	60 % (*n*=43)	55% (*n*=42)	77% (*n*=43)	78.8%
Borderline (3)	15 % (*n*=11)	20 % (*n*=15)	11% (*n*= 6)	10.1%
Abnormal (4-10)	25 % (*n*=18)	25 % (*n*=19)	13% (*n*=7)	11.1%
Total Difficulties				
Normal (0-13)	65% (*n*=47)	71% (*n*=54)	89% (*n*=50)	81.7%
Borderline (14-16)	8% (*n*=6)	13% (*n*=10)	4% (*n*=2)	8.5%
Abnormal (17-40)	26 % (*n*=19)	16% (*n*=12)	7% (*n*=4)	9.8%
Prosocial Behaviour				
Normal (6-10)	82% (*n*=59)	86% (*n*=65)	96% (*n*=54)	95.4%
Borderline (5)	10% (*n*=7)	9% (*n*=7)	4% (*n*=2)	2.6%
Abnormal (0-4)	8% (*n*=6)	5% (*n*=4)	- (*n*=0)	2.0%

The distribution of scores for those experiencing one or more significant difficulty at an abnormal level over the range of subscales constituting SDQ Total Difficulties are shown in Table 10. *Z* tests were conducted in order to explore if the difference between the proportions of siblings experiencing a difficulty of clinical relevance i.e. in the Abnormal range, in at least one subscale varied significantly between groups. No statistically significant difference was found. However, a significant difference was found between the proportions of siblings experiencing clinically significant difficulties, in two or more domains, with a significantly higher proportion of siblings of children with ASC experiencing difficulties at this level compared to siblings in the control group (z=2.81, p=.005) but not when compared to siblings of children with DS. The difference between siblings of children with DS and control group siblings was not significant at the p<.01 level (z=2.04, p=.04).

Table 10

Summary of distribution of clinical significant difficulties across Groups

Difficulties* at Abnormal Level	**ASC**	**DS**	**Control**
At least 1	32 (44.4%)	27 (35.5%)	17 (30.6%)
2 or more	19 (26.4%)	15 (19.7%)	4 (7.14%)

Note. **Conduct Problems, Peer Problems*. *Hyperactivity, Emotional Symptoms*.

School level Factors

Preliminary analyses of School Factor Outcomes

Tests of normality were conducted on the data from all three questionnaires relating to school factors: Teacher relationship, SOSB and social dissatisfaction. The data from all three measures had sufficient linearity and homoscedasticity for subsequent parametric analysis.

Data on all three-school measures was converted into z scores in order to check for outlier. No significant outliers were identified.

School Factors: Outcomes

Results from the one way ANOVAs carried out found no evidence of significant between group differences on a measure of SOSB (F[2,201] = 1.30, *p*= .274), Teacher Relationship (F(2, 201) = 1.92, *p* = .149) and Social dissatisfaction (F[2, 201]= .398, *p* =.67).

Table 11

Group means on School Factor measures

	Group		
	ASC	DS	Control
Variables	M (SD)	M (SD)	M (SD)
SOSB	2.70 (.20)	2.66 (.25)	2.60 (.16)
Teacher Relationship	26.73 (3.27)	27.62 (2.78)	26.73 (3.22)
Social dissatisfaction	28.75 (4.16)	28.43 (4.22)	29.14 (5.24)

Note. *M = Mean, SD = Standard Deviation*

School Factors: Correlations with Siblings Adjustment

The Spearman's rank order correlation coefficients or Pearson's Correlation Coefficient were computed between the three school variables and all SDQ subscales, for each sibling group.

Siblings of children with ASC. For siblings of children with ASC, no significant correlations were found, with all ps >.01. However a near significant positive correlation was found between Peer Problems and social dissatisfaction (r(70)=.241, *p*=.043).

Siblings of children with DS. For siblings of children with DS, significant positive correlations were found between social dissatisfaction and SDQ Total Difficulties score (r(74) = .285, *p*=.01), Conduct Problems (r(74)=.353, *p*=.002) and Peer Problems (r(74)= .319, *p*=.003). All other correlations were non-significant.

Control Siblings. For siblings of TD children a significant negative correlation was found between SOSB and Emotional symptoms (r(54)=-.343, *p*=.010). A positive correlation between social dissatisfaction and SDQ Peer problems approached significance (r(54) =.307, *p* =.021).

Family Factors

Preliminary analyses of Family Factor Outcomes

Tests of normality were conducted on the data from questionnaires relating to family factors. Assumptions of normality were met for the following measures: DASS Depression, DASS Total and the UCLA. The anxiety subscale of the DASS (z skewness = 2.01 to 7.51, z Kurtosis = -0.99 to 7.56) and Stress subscale of the DASS (z skewness= 1.77 to 3.82, z kurtosis = 0.141 to 4.38) were positively skewed, and thus subjected to a Sqrt transformation. Following transformation scores from both scales: stress and anxiety, were found to meet assumptions of linearity and homoscedasticity allowing for subsequent parametric analysis. No cases were excluded from the data set, as there were no missing data. Examination of z scores revealed no significant outliers.

Family Factors: Outcomes

A significant group difference was found between parent levels of reported loneliness (UCLA) (F(2,201) = 17.52, *p*=<.001). Hochberg post-hoc analysis showed parents of children with ASC and DS reported higher levels of loneliness when compared to parents of children with no disability (*p*<.001) (DS r = 0.43; ASC r = 0.52). No significant difference was found between parents of children with DS and ASC (*p*>0.01).

No significant group differences were found in relation to parent levels of reported stress (F[2,201]=.42, p=.66), anxiety (F[2,201]=.04, p=.96) and total difficulties (DASS total) , (F[2,201]=1.64, p=.19). The difference between parent scores on the DASS depression subscale approached significance (F[2,201] = 3.23, p=.04); this was not significant in post hoc analysis. Group means are presented in table 12.

Table 12

Group means on Family Factors

	Group		
	ASC	DS	Control
Variables	M (SD)	M (SD)	M (SD)
DASS Depression	4.83 (2.88)	3.82 (2.55)	3.91 (2.31)
DASS Stress	5.90 (3.20)	5.63 (2.90)	5.30 (2.74)
DASS Anxiety	2.83 (2.92)	2.52 (1.92)	2.60 (1.98)
DASS Total	13.57 (7.58)	11.99 (6.16)	11.82 (4.04)
UCLA	38.99 (5.36)	39.12 (6.08)	34.07 (4.21)

Note. M = Mean, SD = Standard Deviation

Family Factors: Correlates with Siblings Adjustment

Siblings of children with DS. Results revealed several correlations between parent wellbeing and sibling adjustment. The strongest positive correlation was between parents ULCA score and siblings SDQ total difficulties score (r(74) = .419, p = <.001). Further small, but significant positive correlations were found between parents reported loneliness and siblings SDQ Conduct Problems scores (r(74) =.320, p = .005) and siblings SDQ Emotional Symptoms score (r(74) =.346, p = .002).

Siblings of children with ASC. For siblings of children with an ASC, a significant positive correlation was found between DASS anxiety and siblings SDQ Conduct Problems score (r(70)=.319, p = .007). Five correlations were found to be approaching significance. This included a positive correlation between parents total DASS score, and siblings SDQ Total Difficulties score (r(70)=.251, p=.04), a positive correlation between parents DASS anxiety, and siblings SDQ Emotional Symptoms score (r(70)=.284, p=.02) and siblings Hyperactivity score (r(70)=.235, p=.049). Lastly negative correlations which approached significance were found between parents DASS anxiety score and siblings Prosocial behaviour score (r(70)=-

.263, p=.026) and parents DASS total and siblings Proscoial behaviour score (r(70)=-.267, .024).

Control Siblings. No significant correlations were found between parents ULCA score, parents DASS scores and sibling adjustment in the control group.

Individual Factors

Preliminary analyses of Individual Factors

Tests of normality were conducted on the data for individual factors. All data was found to have sufficient linearity and homoscedasticity for a subsequent parametric analysis.

Individual Factors: Outcomes

Given that the individual factors investigated were specific to siblings of children with disabilities (focus groups), the two focus groups only were compared on individual factors.

Independent sample t-tests were used to compare the two focus groups on 6 variables. As shown in Table 13, parents of children with an ASC reported treating reference and target siblings differently significantly more than parents of children with DS. Siblings of children with DS, as reported by both parents and siblings themselves, felt significantly more satisfied with the treatment they receive from their parents compared to siblings of children with ASC. No significant group differences were found on the measure of knowledge of disability.

Table 13

Results of t-tests for Individual Factors by Focus Group

	DS (n=76)		ASC (n=72)				
	M	SD	M	SD	*p*	*t*	*df*
Differential Parenting Index							
Differential Parenting Treatment – Parent report	3.17	.84	3.78	.81	.001	-4.47	146
Differential Parenting Treatment – Sibling report	2.87	.87	3.19	1.03	.039	-2.08	146
Sibling satisfaction with Differential Parenting – Parent report	3.72	.67	2.94	.79	.001	6.52	146
Sibling satisfaction with Differential Parenting – Sibling report	3.5	.90	2.94	.77	.001	3.99	146
Knowledge of Disability							
Parent report	6.00	1.84	6.15	1.58	.59	-.54	146
Sibling report	6.33	2.10	5.86	1.97	.17	1.40	146

Note. M =Mean. SD = Standard Deviation

Individual Factors: Correlates with Sibling Adjustment

Siblings of children with DS. For siblings of children with DS, no significant correlations were found, with all ps >.01 There was a near significant correlation between knowledge of disability (as reported by parents) and SDQ peer problems (r=(74) =-.247, *p*=.031).

Siblings of children with ASC. No significant correlations were found at the p<.01 level.

Predicting Sibling Adjustment

Siblings of Children with DS. Using Regression (Enter) to model the relationship between school level factors and sibling adjustment, no school level factors were found to account for a significant proportion of sibling adjustment (SDQ total difficulties, SDQ emotional symptoms, SDQ conduct difficulties). Parents ULCA score explained 17% of siblings SDQ total difficulties score (F[1,74]=15.73, *p* =.001), 15% of siblings conduct difficulties (F[1,74]=13.47, *p* =.001) and 12% of siblings emotional symptoms (F[1,74]=10.05, *p*=.002).

Siblings of children with ASC. For siblings of children with ASC, no school level factors were found to explain a significant proportion of variance in sibling adjustment. Parental anxiety explained 9% of siblings conduct difficulties (F[1,70]=7.10, p=.010).

Control Siblings. For siblings of TD children, SOSB was found to explain 11% of siblings emotional symptoms, which was significant F(1,54)=7.18, p=.010. No other results were significant.

Overall school level variables did not explain a significant proportion of adjustment in siblings of children with ASC and DS. Given that school factors did not explain a significant proportion of variance, hypothesis 4 was not explored and a multiple hierarchical regression analysis not conducted.

Discussion

Previous research exploring the adjustment of sibling of children with a disability, presents mixed findings (Gaillo & Gavidia-Payne, 2006) with some siblings appearing well adjusted (Rossiter & Sharpe, 2001) whilst others are vulnerable to poor psychological wellbeing (Hastings, 2003; Jones, Welsh, Glassmire & Tavegia, 2006). Methodological factors, including the use of mixed disability groups, and siblings of large age ranges may have contributed to the mixed findings (Cuskelly, 1999; Hodapp et al., 2005; Stoneman, 2005) in previous research. The current study aimed to overcome previously levelled criticisms by investigating the Social Emotional and Behavioural (SEB) adjustment of siblings of children with two specific disabilities; siblings of children with Autistic Spectrum Condition (ASC) and sibling of children with Down syndrome (DS). All siblings were aged 7 to 11, thus constituting a narrower age range than in previous studies. The second aim of the present study was to investigate the association between sibling adjustment and three previously unexplored school level factors; peer relationships, teacher relationships and Sense of School Belonging. In domains other than the sibling literature these school level factors have been found to have a protective role thus promoting positive adjustment.

This section provides a brief overview of the key findingings, relating to the aforementioned aims of the study. Potentail explanations for findings are offered. Limitations of the research are discussed and avenues for future research identified. Finally, implications for Educational Psychologists and other professionals, including teachers, are outlined.

Hypothesis 1 was partially supported; siblings of children with an ASC showed significantly more emotional symptoms, peer difficulties, hyperactive behaviour and total difficulties as measured by the SDQ than siblings of children with no disability, although the effect sizes were small. This finding is in line with previous research that suggests that siblings of children with an ASC may be at increased risk of adjustment difficulties compared to siblings of TD children (e.g. Hastings, 2000b;

Ross & Cuskelly, 2006). In contrast, with the exception of peer difficulties, as a group, siblings of children with DS were reported to have no greater adjustment difficulties than siblings of TD children. Again, this supports previous, albeit limited, research that suggests that siblings of children with DS may experience fewer difficulties than siblings of children with ASD (e.g., Rodrigue et al., 1993; Fisman et al., 1996). Furthermore, this adds credence to the suggestion that the reliance on mixed disability groups in previous research, may have added to the varied findings within the sibling literature (e.g., Fisman et al, 1996; Bagenholm & Gillberg, 1991).

The current study also explored the extent to which sibling groups are considered to experience clinically significant difficulties. According to the bandings provided by Goodman (1997) siblings of children with ASD had borderline clinically significant emotional symptoms, borderline conduct problems, and borderline peer problems. With the exception of this latter peer problems score, siblings of children with DS, as a group, were found to score within a normal range. This is somewhat different to some previous research that has suggested that whilst siblings may experience difficulties, they are often not of clinical significance (e.g. Rodrigue, Geffken & Morgan, 1993). Interestingly, in one of few studies to report clinically significant difficulties, siblings were aged 6-11 (Verte, Roeyers & Buysse, 2003). It is possible that the increased levels reported in the current study, are therefore associated with younger sibling age, and that adjustment difficulties decrease with age. However, given that this is one of very few studies to consider the adjustment solely of primary school age children, this remains speculative and warrants further research. In addition, in this study 44.4% of siblings of children with an ASD were reported as having a difficulty of clinical significance. This finding is comparable to the 40% reported by Ross and Cuskelly (2006) and those found in other groups considered vulnerable or 'at risk,' for instance, children with pervasive hyperactivity (Sayal, Taylor, Beecham & Byrne, 2002) and children with an Intellectual Disability (ID) (Kaptein, Jansen, Vogels & Reijneveld (2008). Equally, 35% of siblings of children with DS were reported to experience some type of clinical adjustment difficulty, which is higher than would be expected in a normative sample (Achenbach, 1991; Sawyer et al., 2001). This is despite the aforementioned finding that as a group, with the exception of peer difficulties, siblings of children with DS, scored within a normal range. This highlights how studies that have reported only the

mean score of whole groups may have dismissed a subsample of siblings who experience difficulties.

Unlike previous studies, the current study not only compared the proportion of siblings scoring within a clinical range, on each subscale, but also considered the range of subscales, constituting SDQ Total Difficulties, over which siblings scored within a clinical range. Findings showed that a higher proportion of siblings of children with an ASC where reported to have emotional symptoms of clinical significance. This increase in emotional difficulties appears to separate siblings of children with ADS from siblings of children with DS. Whilst it has previously been suggested that siblings of children with a disability may experience more internalising difficulties (Rossiter & Sharpe, 2001; Gaillo & Gavida-Payne-Payne, 2006), this distinction between specific groups, when only clinically significant difficulties are considered, to the authors knowledge has not previously been noted, and thus may be an interesting avenue for future research. Furthermore, findings showed that what appears to differentiate the adjustment of siblings of children with a disability, from control siblings, is the significantly increased proportion of the former who go on to have two or more symptoms of clinical significance. Given the aforementioned hypothesis of age as influencing factors, there is a need for future studies to adopt a longitudinal approach and explore the developmental psychopathology of specific sibling groups.

Previous researchers have offered several explanations for increased adjustment difficulties found in siblings of children with ASD, including temperament differences (Fisman et al., 1996), differences in diagnostic certainty (Fisman, et al., 1996) and the presence of an autism phenotype in siblings of children with ASC, which may represent a predisposed vulnerability to adjustment difficulties in siblings (e.g., Hughes, Plumet & Leboyer, 1999; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, Shalev, 2004). Given the suggestion that it may be an increase in emotional difficulties that distinguish siblings of children with ASD from siblings of children with DS, it would be interesting to explore further the role these various factors may play in mediating and moderating, specifically the emotional adjustment of siblings.

The second aim of the present study was to investigate the extent to which three school levels factors (SOSB, social dissatisfaction, teacher relationship) were associated with and predicted the adjustment of siblings. Results were mixed, with hypothesis 2 only partially supported and hypothesis 3 and 4 rejected. Indeed, no association was found between school factors and the adjustment of siblings of children with an ASD. Whilst social dissatisfaction was found to positively correlate with SDQ total difficulties, SDQ conduct problems and SDQ peer problems, for siblings of children with DS, correlations were weak. Indeed, with the exception of SOSB predicting 11% of sibling adjustment in the control group, school factors did not explain a significant proportion of sibling adjustment. These mixed findings, were despite no group difference being found, and moreover, all groups scores falling within a normal range (Frederickison & Baxter, 2009; Bowen et al., 2005; Cassidy & Asher, 1992).

Overall, the lack of association and predictive value of the investigated school level factors was surprising given research documenting the strong relationship between the identified school factors and children's wellbeing. However, several potential explanations can be offered, all of which may warrant further research. Firstly, these findings may support the suggestion that protective factors may be context specific (Luthar et al., 2000; Criss, Pettit, Bates, Dodge & Lapp, 2002). For instance a SOSB may act as a buffer, and promote social emotional and behavioural wellbeing, for children experiencing certain challenges, such as growing up in care (Jackson & Martin, 1998), but not others. The utility of school factors in promoting sibling wellbeing may therefore depend on whether the particular school factor contains the attribute that is either lacking or deficient in the siblings' environments. Alternatively, Garmezy (1983) suggests that there may not always be direct linear relationships between risk and protective factors and adjustment. Instead it is suggested that a curvilinear mechanism may exist, whereby factors are protective at certain levels of stress, however when the stress becomes high, such factors may no longer have sufficient protective value. Thus the increased difficulties associated with being a sibling of a child with ASC, may cross a threshold whereby the investigated school factors are not protective. Equally, the method employed within the current study may also have impacted on the findings. In particular the current study explored the association between sibling adjustment as reported by parents and

school factors as reported by siblings. It has been suggested that parent's reports of sibling adjustment may be partly based on their own adjustment (Cuskelly, 1999). Therefore the use of different informants may have impacted on the associations found.

Alongside exploring school level factors, the current study investigated the association between parent factors and sibling wellbeing. Results showed parental loneliness appeared to be more closely related to the adjustment of siblings of children with DS while for siblings of children with an ASC, DASS scores measuring parents internalising behaviour appeared to be more poignant in sibling adjustment. This was despite there being no significant group difference in parent scores of loneliness, and only a tendency towards elevated scores of internalising difficulties in parents of children with ASD. Overall, the relationship between parent wellbeing and feelings of social connectedness in the adjustment of siblings is consistent with family systems theory and previous empirical findings (Jackson, Richer & Edge, 2008; Rosenbaum, King, Law, King & Evans, 1998; Turnbull, Turbull, Erwin & Soodak, 2006; Giallo & Gavidia-Payne, 2006). However, the difference between the two groups raises an interesting question in terms of the mechanism through which parental mental health and social support has a different effect on siblings of different disabilities. This is an area that warrants further research attention.

Limitations

There are several methodological limitations to bear in mind when considering the findings of the present study. First, as with most studies considering the adjustment of siblings, the cross sectional study design does not allow cause and effect relationships to be addressed. There is a need for longitudinal research to explore the long-range impact of having a disabled brother or sister on sibling adjustment, as well as exploring how changes in protective and risk variables temporally precede changes in sibling adjustment (Hastings, 2007).

Second, the present study aimed to consider the adjustment of two specific sibling groups. This followed the suggestion that target siblings adjustment may vary according to reference sibling's diagnosis (Fisman, 1999). However, no attempts

were made to consider the reference siblings specific ASC diagnosis, thus target siblings were included irrespective of whether reference siblings were diagnosed with HFA, Asperger syndrome or PDD. This may impact on the extent to which the findings can be generalised to other groups of siblings of children with ASC. Furthermore the over or under representation of a particular subgroup of children with an ASC may have in some way impacted on the high-level of adjustment difficulties reported.

Third, as with previous research, participants were primarily recruited via voluntary sector organisations (e.g., support groups). Moreover, participants were required to volunteer to participate in the study. It therefore seems reasonable to suggest that parents suffering high levels of stress would be unlikely to have volunteered to participate in the study. Indeed, across all groups, parental stress was comparable, and within an average range (Crawford & Henry, 2003). Families who participated may therefore not have been fully representative of all families with a child with a disability. Furthermore, as the majority of the organisations were a form of support group, parents may have been receiving higher levels of support compared to other families, which has been associated with sibling wellbeing (Kaminsky & Dewey, 2002). Overall, the recruitment method may have lead to selection bias amongst participants, creating the potential for responses to differ from those who chose not to participate in the research. Future studies need to seek to recruit a more diverse sample of families, which may be more representative of the population, which they represent. It is acknowledged however that this represents a significant challenge, given the difficulties in recruiting large enough samples from a relatively exclusive source of potential participants.

Fourth, it needs to be acknowledged that the sample size targets (n=111 in each group) were not reached and thus the study may have reduced power. However this needs to be viewed in the context of this being one of few studies considering the adjustment of siblings of children with as ASC or DS with participant numbers of over 50.

Lastly, as noted previously, it may be considered a limitation that measures of adjustment were based on parent reports only and may be considered a threat to the

validity of findings. Nevertheless, interesting differences have arisen between groups based on parental measures of sibling adjustment. Specifically, group differences were identified in the severity of emotional symptoms, the number of clinically significant difficulties and the relationship between self-reports of parental mental health and parent informed measures of sibling adjustment.

Implications for Research

Despite the limitations of the current study and the rejection of many of the studies hypothesis the current study has important implications for both practice and future research. The present study represents part of an important paradigm shift, with a move from pathology to resilience, and a shift in focus from static variables (e.g., gender) to a focus on dynamic variables (e.g., coping styles) (Ross & Cuskelly, 2006). Future research should continue to explore dynamic variables that may support an explanation of sibling adjustment. Given the theoretical argument outlined in the introduction, further consideration should be given to factors in the wider society, including school factors. In particular, there is a need for the school level factors explored in the current study, to be considered across different age ranges. This follows the suggestion that the importance of SOSB and peer relationships may increase as children mature (Drolet, Arcand, Ducharme & Leblanc, 2013), and thus these variables may hold more predictive value in an older sibling sample.

The current study strived to increase the reliability of findings, by considering previously raised methodological concerns (Cuskelly, 1999). In particular the study separated siblings into groups, according to the diagnosis of the reference sibling. Given the difference in findings between focus groups this is an avenue which researchers should to continue to explore, as well as the mediators and moderators which underlie differential outcomes.

Future research needs to work to overcome some of the criticism raised within the current study, including triangulating measures of outcome. In particular, the association between school level factors and sibling adjustment, as reported by siblings should be explored. Given the focus on school level factors, it may of value to also incorporate a teacher completed measure of adjustment. Using the parent,

teacher and the self-report version of the SDQ, would allow the same measure to be used across informants.

Professionals Implications

There are several implications for practice for Educational Psychologists (EPs) Firstly; the present study highlights the need for EPs to be aware of the potential for siblings, particularly of children with an ASC, to be at an increased risk of adjustment difficulties. EPs may be well placed to share this understanding with other professionals, for example class teachers, who may be involved in both identifying and supporting siblings. Specifically, it may be of value for EPs to increase teachers understanding and attention to internalising difficulties, as such difficulties are often overlooked in comparison to externalising problems (Berk, 2006; Silverman & Treffers, 2001). Secondly, the clinically significant difficulties experienced by some siblings may lead to the need for EPs to become involved with direct intervention work. However, such intervention must be evidence-based and research led. Therefore it is important that EPs continue to strive to understand how specific factors may impact on sibling adjustment. EPs may be well placed to continue developing this evidence base. Lastly, as noted previously, the embedding of sibling wellbeing within a resilience model reflects a movement towards a focus on adaptation and development as opposed to deficit and damage. EPs have a fundamental role in supporting other professionals to view the adjustment of siblings as dynamic and evolving and thus with potential for positive change.

Conclusion

In summary, the current study highlights the complexity of sibling adjustment. The findings suggest that siblings of children with an ASC may be at increased risk of developing adjustment difficulties compared to siblings of children with DS and control siblings. Specifically, siblings of children with ASD may be vulnerable to developing emotional difficulties of clinical significance. Whilst siblings of children with ASD appear to be at greater risk of adjustment difficulties, there is a trend towards increased clinical difficulties, over a range of difficulties for siblings of both focus groups. The high level of adjustment difficulties reported in the current study may be associated with the young age of participating siblings.

Guided by a risk and resilience model, and Bronfenbrenner's Ecological Systems Theory the current study aimed to investigate the association between previously unexplored school level factors and sibling adjustment. The results appear mixed. Whilst some associations were found between school factors and sibling wellbeing, across focus groups these variables did not explain a significant proportion of variance in sibling adjustment. Potential explanations for this finding include the underlying mechanisms of the considered protective factors differing from the underlying risk factor, and the reliance on parents as informants of sibling adjustment.

The results emphasise a need for evidence-based interventions to support the wellbeing of siblings. Also, highlighted is the need for longitudinal research to explore the developmental psychopathology of homogenous sibling groups, alongside mediators and moderators, which underline differential adjustment outcomes. Variables should continue to be identified from all ecological layers (e.g., individual, family, school, wider society). Future research should expand the current study by exploring the association between school level factors and sibling adjustment, as reported by siblings themselves, with sibling populations of varying ages considered.

Appendices

Appendix A: Data extraction table of included studies

Study/ Focus (paper number)	Location	Methods TD siblings (TD) ASC sibs DS sibs	Informants	Outcome Measures	Main Findings Effect size detailed when reported or calculated
Bagenholm and Gillberg (1991) (1) To explore the adjustment of siblings of children with ASC in comparison to siblings of children with mental retardation (ID) and siblings of children with no disability. Cross-sectional (Mixed methods)		**Sample:** 20 siblings of children with ASC (12M/8F), 20 siblings of children with ID (12M/8F) and 20 siblings of children with no disability (12M/8F). **Age target sibs:** 5 – 20 **Age reference sibs:** 5-20 Children with ASD: 12M/8F Children with ID: 12M/8F Children with no disability: 12M/8F **Reference sib diagnosis**: ASC **Control Group:** Siblings of children with ID and siblings of TD children	**Informants:** Mothers and siblings	**Measures:** Semi structured interview Piers-Harris Children's self concept scale Rutter Scale	**Findings:** Siblings of children with a disability (ASD & ID) were reported as having more behavior difficulties, than siblings of TD children. Siblings (35%) of children with ASD reported feeling lonely and increased levels of peer difficulties. There was no difference in the self concept of the siblings between the three groups No association between sibling adjustment, age and birth order.

Cebula (2012) (2) To investigate the psychosocial adjustment of siblings of children with ASC whose families were using a home-based ABA intervention. Cross sectional	**Location:** UK	**Sample:** 45 TD siblings of children with ASC using ABA (21M/24F). 26 TD siblings of children with an ASC who had previously used ABA (15M/11F). 61 TD siblings of children with ASC not using ABA or having previously used ABA (18M/27F). **Age target siblings**: 4-16 **Age reference siblings**: Mean age 7.25-8.92 (99M/17F) **Reference sib diagnosis:** ASC, Asperger syndrome, HFA **Control Group:** ABA involvement/ non ABA involvement	**Informants:** Parents, Siblings (age dependent), teachers	**Measures:** Strengths and Difficulties Questionnaire (SDQ) Sibling Inventory of Behavior Piers-Harris Children's Self Concept Scale	**Findings:** Siblings in ABA families experienced neither significant drawbacks nor benefits in terms of their behavioural adjustment, sibling relationship quality and self-concept compared to control group siblings, either during or following intervention use. Proportions of siblings in the 'abnormal' range was similar the 10% suggested by Goodman (1997). Social support was associated with better outcomes (self-concept) in all groups. No correlation between parenting stress and sibling adjustment level. Autism symptom severity was not related to sibling adjustment. ABA and ABA controls (Parent) Emotional Problems: ES = 0.14 Conduct Problems: ES = 0.05

					Total Score: ES = 0.08 ABA and ABA controls (Sibling data) Emotional Problems: ES = 0.19 Conduct Problems: ES = 0.05 Total Score ES = 0.20 ABA and ABA controls (Teacher Data) Emotional Problems: ES = 0.39 Conduct Problems: ES = 0.13 Total Score: ES = 0.35
Cuskelly, Chant and Hayes (1998) (3) To explore the behavioral adjustment of siblings of children with DS. Cross sectional	**Location:** Australia	**Sample:** 44 TD siblings of children with DS, 88 TD siblings of children with no disability. (Gender not reported) **Age target sibs:** 4 – 18 **Age reference sibs**: 4 – 15 **Reference sib diagnosis**: DS **Control Group:** TD siblings of TD children.	**Informants:** Mothers and Fathers	**Measures:** Child Behavior Checklist (CBCL)	**Findings:** There were no differences between the siblings of children with DS and comparison children on mothers' or fathers' reports of problem behaviour (ES = 0.06-0.40). There was substantial concordance between mothers and fathers report, in respect of the child identified as having the most problems on each of the scales. There was a significant positive correlation between parents stress and poor sibling well

					being For brothers of a child with DS (on fathers reports), there were significant negative correlation between household tasks and behavior problems.
Cuskelly and Dadd (1992) (4) To investigate the occurrence of problem behaviours in children with DS, and their siblings. Cross sectional	Australia	**Sample:** 21 TD siblings of children with DS (9M,12F). 21 children with DS (12M, 9F) **Age target sibs:** 5 – 16 **Age reference sibs:** 4 – 15 (12M,9F) **Reference sib diagnosis**: DS **Control Group:** Comparison made to children with DS	**Informants:** Mothers and Fathers	**Measures:** The revised problem checklist (RBPC) Beck Depression Inventory (BDI) Dyadic Adjustment Scale (DAS)	**Findings:** Female siblings were reported to show more conduct difficulties than male siblings, by all rates (mothers, parents, teachers) (ES = 0.15- 0.68). 7 out of the 12 sisters were reported to be two or more standard deviations above the mean on the conduct disordered subscale. Only 1 brother, out of 9, had a score two or more standard deviation above the mean. Parental depression contributed significantly to both parent's (mothers and fathers) reports of problem behaviours in siblings. Marital satisfaction did not contribute to reports of sibling problems. No relationship between the

					child with DS behaviour and the target sibling's adjustment.
Cuskelly and Gunn (1993) (5) To investigate maternal reports of behavior difficulties in siblings of children with DS Cross Sectional (Mixed methods)	Australia	**Sample:** 70 siblings of children with DS (33M, 37F). 70 siblings of children with no disability (22M, 48F) **Age target sibs:** 6 – 13 **Age reference sibs:** 6-13 (22M, 48F) **Reference sib diagnosis**: DS **Control Group:** Siblings of children with no disability	**Informants:** Mothers and Siblings	**Measures:** Semi structured interviews Conduct disorder subscale of the Revised Problem Behaviour Checklist	**Findings:** Mothers reported that girls who had siblings with DS were more likely than siblings of children with no disability to show increased conduct difficulties. Conduct disorder: (siblings vs comparison female/female): ES = 0.605 Conduct disorder: (siblings vs comparison males/males): ES = 0.010 Conduct disorder (siblings female/male): ES = 0.360 No association was found with birth order, family size and adjustment difficulties. An inverse relationship was found between household responsibility and sibling adjustment, although siblings were not reported to undertake an increased amount of household responsibilities.

Cuskelly and Gunn (2006) (6) To investigate the adjustment of typically developing siblings of children with DS. Cross sectional	Australia	**Sample:** 53 TD siblings of children with DS (28M/25F). **Age target sibs:** 7 – 14 **Age reference sibs:** 5.5 – 18 **Reference sib diagnosis**: DS **Control Group:** Siblings of children with no disability.	**Informants:** Parents and Siblings	**Measures:** Child behaviour checklist (CBCL) The Self-Perception profile for children (SPPC) Telephone semi-structured interview	**Findings:** There were no significant adjustment differences between the siblings of children with DS and the siblings of TD children on any of the measures of adjustment –behaviour, competence and self-concept. Mean CBCL scores were below the clinical range for problem behaviours for both groups. No differences in relationship with peers or academic achievement between groups. There was an association between parental reports of externalizing behaviour and sibling relationships with the brother/sister closest in age. No gender differences Siblings of Children with DS and TD Sibling group (males): Internalising (mother): ES = 0.38 Internalising (father): ES= 1.54 Externalising (mother): ES= 0.35 Externalising (Father): ES =

					0.46 Siblings of Children with DS and TD Sibling group (females): Internalising (mother):ES = 0.26 Internalising (father): ES = 0.03 Externalising (mother): ES = 0.33 Externalising (Father):ES = 0.30
Dempsey, Llorens, Brewton, Mulchandani & Goinkochel (2012) (7) To use parent and teacher reports to describe presence of internalizing and externalizing behaviors among a large sample of TD siblings of children with an ASC. Cross sectional	USA	**Sample:** 486 TD siblings of children with an ASC (218M/268F) **Age target sibs:** 6 – 18 **Age reference sibs**: 4 – 18 (418M/68F) **Reference sib diagnosis**: ASC **Control Group:** Normative Data	**Informants:** Parents and Teachers	**Measures:** Child Behaviour Checklist (CBCL) Child Behaviour Checklist-teacher report form (TRF) Calibrated Severity Score (CSS)	**Findings:** Neither teachers nor parents reported elevated internalizing (ES= 0.13/ ES 0.26) or externalizing problems (ES = 0.32/ ES= 0.32) among siblings. Siblings showed, less difficulties than normative data. Findings indicated that agreement between raters (parents and teachers) on measures of internalizing and externalizing symptoms was low.

Gath & Gumley (1987) (8) To investigate the behavioural and academic adjustment of siblings of children with DS and children with an unspecified disability. Cross sectional	UK	**Sample:** 95 Siblings of children with DS (45M/50F), 8 siblings of children with an unspecified disability. **Age target sibs:** Mean age 10 years, 10 months **Age reference sibs:** Mean age 10 years, 3 months (53M, 42F) **Reference sib diagnosis:** DS **Control Group:** Siblings of children with an unspecified disability. TD classroom controls.	**Informants:** Parents and Teacher	**Measures:** Rutter Behaviour Scale Rutter Scale (B2)	**Findings:** Mothers of children with DS were more likely to believe that their TD sibling had emotional problems, even when they identified few behaviour problems. There was an assumption that the TD sib had hidden emotional problems despite apparently normal behaviour. There was little difference between the TD sibs of children with DS and the classroom controls in the proportions who had deviant scores of 9 or more on the Rutter B2 scale. No association between age, birth order, gender, marital satisfactions and sibling adjustment. A warm and cohesive home acted as a protective factor when the outcomes of siblings of children with DS and siblings of children with another disability were considered together Positive correlation between

					behaviour problems in the child with DS sibling adjustment. Positive correlation between the child with DS's level of competence, and TD sibling's positive behavioural adjustment.
Gold (1993) (9) To compare siblings of boys with an ASC, and siblings of children with no disability on a measure of depression and social adjustment. Cross sectional	Canada	**Sample:** 22 Siblings of boys with ASC (11F/11M), 34 siblings of children with no disability. **Age target sibs:** 7 – 17 **Age reference sibs:** 7 – 17 (Boys only) **Reference sib diagnosis**: ASC **Control Group:** Siblings of children with no disability	**Informants:** Parents and Siblings	**Measures:** Children's Depression Inventory (CDI) Child Behavior Checklist (CBCL)	**Findings:** Siblings of boys with an ASC scored significantly higher on a measure of depression than a comparison group (ES 0.58. No significant differences in social competence or behavior adjustment (ES=0.03-0.06). There were no statistically significant gender differences, however the correlates of depression differed for brother and sister. This suggests the factors contributing to the depression may be different. Family type did not impact on social adjustment or depression score. However older siblings reported higher levels of depression. There was a

					significant birth order and gender effect. Siblings who reported having nobody to talk to about their sibling with an ASC scored significantly higher on a measure of depression. Positive correlation between maternal 'feelings of burden' (e.g. finding her caregiving responsibilities difficult to manage) and ASC siblings levels of depressive symptoms.
Griffith, Hastings and Petalas (2014) (10) To examine mother-father agreement on the behavioural and emotional adjustment of siblings of children with Autism. Cross sectional	UK	**Sample:** 168 siblings of children with an ASC (85M/83F) **Age target sibs:** 4 to 17 **Age reference sibs:** 4 to 17 (138M/30F) **Reference sib diagnosis**: ASC (most had a diagnosis of Asperger's) **Control Group:** Normative data	**Informants:** Mothers and Fathers	**Measures:** The Strengths and Difficulties Questionnaire (SDQ)	**Findings:** Mothers rated siblings as having significantly more overall adjustment problems (ES= .22), emotional problems (ES =.38) and conduct problems (ES =.30) , alongside lower levels of pro-social behaviour (ES = .33) when compared to a normative sample. A significantly higher proportion of siblings had scores in the abnormal clinical range, than in the normative

					sample. Fathers rated sibling as having significantly more emotional problems (ES =.22) and lower levels of pro-social behaviour (ES .36) when compared with the normative sample. The proportion of siblings reported to be in the abnormal clinical range was significantly higher (3 x as many siblings) for emotional problems and prosoical behaviour compared to the normative sample. No statistically significant differences were found in mother and fathers ratings on SDQ peer problem domains.
Fisman, Wolf, Ellison & Freeman (2000) (11) To compare the adjustment of siblings of children with PDD, DS and siblings of children with no disability, across a 3 year span.	Canada	**Sample:** 42 siblings of children with PDD (16M/,26F), 45 siblings of children with DS (17M, 28F) 46 siblings of TD children (18M,28F) **Age target sibs:** 8 -16 **Age reference sibs:** 4-18 Children with DS (21M/24F) Children with PDD (35M/7F) **Reference sib diagnosis**:	**Informants:** Parents, teachers, siblings	**Measures:** The survey diagnostic instrument (adapted from CBCL) Beck depression inventory (BDI)	**Findings:** Siblings of children with PDD were reported as having more adjustment difficulties (particularly externalizing) over time than siblings in the DS or control group. Parental distress acted as a mediator for siblings of children with PDD adjustment

Longitudinal Cross sectional		PDD, DS **Control Group:** ASC/DS and siblings of TD children			difficulties over time. The longitudinal study supported the risk of adjustment difficulties in siblings of children with PDD
Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari (1996) (12) To examine the adjustment of nondisabled siblings of handicapped children Cross sectional	UK and Canada	**Sample:** 45 siblings of children with PDD (18M/27F), 45 siblings of children with DS (17M/28F) and 45 siblings of TD children (18M/27F) **Age target sibs:** 8 - 16 **Age reference sibs:** 4 - 18 Children with: DS (22M/23F) PDD (37M/8F) **Reference sib diagnosis**: PDD, DS **Control Group:** TD siblings of TD children	**Informants:** Parents and Teacher	**Measures:** Self-Perception profile for children The Dyadic Adjustment Scale The Beck Depression Inventory	**Findings:** Significantly more internalising and externalising difficulties were reported by parents, for siblings of children with PDD, compared to the other two groups. Teachers reported significantly more externalising difficulties only. Marital satisfaction, lack of parental depression, a cohesive family, and a warm, nonconflictual sibling relationship were protective for normal control and Down Syndrome siblings but not for PDD siblings. Parental distress mediated the relationship between group membership and parental reports of internalising and externalising behaviour. Sibling relationships associated

					with adjustment of siblings of children with DS, but not PDD.
Hastings (2003a) (13) To investigate the psychological adjustment of siblings of children with ASC engaged in intensive ABA early intervention programs. Cross sectional	UK	**Sample:** 78 siblings of children with an ASC (37M/41F) **Age target sibs:** 4-16 **Age reference sibs:** 4-16 (69M/9F) **Reference sib diagnosis**: ASC **Control Group:** Normative data	**Informant:** Mothers	**Measures:** Strengths and Difficulties Questionnaire (SDQ)	**Findings:** There was no evidence of a negative impact on TD sibling of having a sibling with ASC engaged in ABA. Siblings differed significantly from the normative data on there of the SDQ problem domains. In each case, typically developing siblings were reported as having fewer problems. ES 0.27 (Hyperactivity) – 0.56 (Total Score) Siblings in families with children with autism who exhibited less severe behaviour had fewer adjustment problems when formal social support was available to the family Older siblings were reported as having more pro-social behavior. No gender differences in outcome.

Hastings (2003b) (14) To investigate factors pertinent to the adjustment of siblings of children with an ASC. Cross sectional	UK	**Sample:** 26 siblings of children with an ASC (Gender not reported) **Age target sibs:** 4-16 **Age reference sibs:** 4-16(17M,9F) **Reference sib diagnosis**: ASC **Control Group:** Normative data	**Informants:** Mothers, Teachers (asked about child with ASC only)	**Measures:** Strengths and Difficulties Questionnaire (SDQ)	**Findings:** Siblings of children with an ASC were at increased risk of adjustment difficulties compared to a normative sample. This included emotional problems (ES 0.44), Conduct problems (ES=.36), Hyperactivity (ES=.30), Peer problems (ES=.33), prosocial behavior (ES =.24) and Total score (ES=.33). Brothers and younger children engaged in fewer pro-social behavior, but no differences in internalizing or externalizing. No differences associated with birth order. Maternal stress and behavior of the disabled sibling were related to, but did not add significantly to the prediction of sibling adjustment.

Hesse, Danko & Budd (2013) (15) To examine the adjustment of siblings of children with ASC and consider possible predictors of sibling adjustment including, parent functioning. Cross sectional	USA	**Sample:** 200 siblings of children with ASC (100M, 100F) **Age target sibs:** 4 – 10 **Age reference sibs:** 4-10 (174M, 26F) **Reference sib diagnosis**: ASC **Control Group:** Normative data	**Informants:** Parents	**Measures:** Strengths and Difficulties Questionnaire	**Findings:** The level of adjustment difficulties for siblings of children with ASC was significantly higher when compared to normative data Females were found to be better adjusted than males. Higher SES was associated with better adjustment. Parental involvement in therapy and school, parental self-efficacy, and parental stress in families of children with autism did not significantly predict sibling adjustment Parental satisfaction with the role of caregiving for the child with ASC was found to predict adjustment levels in siblings of children with autism, as was sibling gender and family income. Parental stress and parental self-efficacy were not unique contributors to sibling adjustment when other parental variables were considered.

Kaminsky and Dewey (2002) (16) To explore the psychosocial adjustment of siblings of children with ASC, DS and TD children Cross sectional	Canada	**Sample:** 90 TD siblings of children with ASC, DS and TD siblings. Gender ratio's of individual groups not reported: over 50%M **Age target sibs:** 8-18 **Age reference sibs:** 8-18 **Reference sib diagnosis**: ASC, DS. Children with Asperger syndrome and PDD were not included. **Control Group:** Siblings of TD children	**Informants:** Siblings and parents	**Measures:** Child behavior checklist (CBCL)	**Findings:** All siblings, irrespective of group were reported as being well adjusted. All groups reported high levels of social support. Siblings of children with ASC and TD: Total Adjustment ES = 0.01 Externalizing ES = 0.38 Internalizing ES = 0.31 Siblings of children with DS and TD: Total Adjustment ES = 0.06 Externalizing ES = 0.22 Internalizing ES = 0.15 Siblings of children with ASC and siblings of children with DS: Total Adjustment ES = 0.04 Externalizing = 0.12 Internalizing = 0.41 All siblings had low levels of reported loneliness. No deficits in social competence across groups. Sisters of children with ASC

					reported higher social competence than brothers of children with ASC. Brothers of children with ASC reported lowest levels of social competence. No gender differences in internalizing or externalizing behavior. Larger families reported higher levels of positive adjustment. No differences associated with birth order.
Macks and Reeve (2007) (17) To investigate the psychosocial and emotional adjustment of siblings of children with autism and siblings of typically developing children Cross sectional	USA	**Sample:** 51 Siblings of children with an ASC (21M, 30F), 36 siblings of TD children (16M/20F) **Age target sibs:** 7-17 **Age reference sibs:** 7-17 (Gender not reported) **Reference sib diagnosis**: ASC. Siblings of children with Asperger syndrome and PDD were not included. **Control Group:** Siblings of TD children	**Informants:** Siblings and parents	**Measures:** Children depression inventory (CDI-S) Piers-Harris Children's Self Concept Scale Behavior Assessment Systems for Children-Parent Rating Scale (BASC-PRS)	**Findings:** There was no significant difference between groups on CDI-S score or BASC-PRS. Siblings of children with ASC scored significantly higher on the Piers-Harris Children's Self concept score. Demographic risk factors predicted psychosocial and emotional adjustment for siblings of children with autism but not for siblings of TD children.

					Siblings at higher risk for SEB and academic difficulties included males, low SES, having only one sibling, and being older than the child with autism. Siblings at low risk for SEB and academic difficulties included females, high SES, having multiple siblings, and being younger than the child with autism.
Mascha and Boucher (2006) (18) To explore the experiences and feelings of TD sibs of children with anASC Cross sectional (Qualitative)	UK	**Sample:** 14 Siblings of children with ASC (4M, 10F) **Age target sibs:** 11-18 **Age reference sibs:** 7-20 (Gender not reported) **Reference sib diagnosis**: ASC, Asperger syndrome **Control Group:** None	**Informants:** TD Siblings	**Measures:** Semi-structured interviews exploring typically developing siblings thoughts and feelings about their siblings with an ASC.	**Findings:** TD siblings reported difficulties due to the aggressive behaviour of their siblings. Siblings reported that they often felt embarrassed by their sibling's behaviour – indeed this was the most frequently reported negative experience. 10 TD siblings identified a positive aspect of having a brother or sister with ASC.

Mates (1990) (19) To explore the adjustment of siblings of children with an ASC and factors which influence adjustment. Cross sectional	USA	**Sample:** 33 siblings of children with ASC (18M, 15F) **Age target sibs:** 5 to 17 **Age reference sibs:** 5 to 17 (gender not reported) **Reference sib diagnosis**: ASC **Control Group:** Normative Sample	**Informants:** Parents and Teachers	**Measures:** The Piers Harris Self Concept scale The Rutter questionnaire for parents The Rutter questionnaire for teachers	**Findings:** Siblings appeared well adjusted, with no significant difference when compared to a control group. Siblings had significantly higher self concepts scores. Results indicated that there was little variance as a function of gender or family size.
Moyson and Roeyers (2011) (20) To investigate how siblings of children with ASC describe and define their quality of life. Cross Sectional (Qualitative)	Belgium	**Sample:** 17 siblings of children with ASC (10F, 7M) **Age target sibs:** 6 to 14 **Age reference sibs:** 5 to 16 (All Male) **Reference sib diagnosis**: ASC **Control Group:** None	**Informant:** Siblings	**Measures:** Semi-structured interviews	**Findings:** Siblings reported that the behavior of the child with a ASC can be difficult to live with. Siblings emphasized the importance of being able to do things with their sibling, but also having sufficient private time. Siblings appreciated having opportunities to meet other siblings of children with ASC. Siblings felt that the invisibility of ASC could be difficult to manage.

Orsmond and Seltzer (2009) (21) To test a diatheses-stress model of well-being for siblings who have a brother or sister with ASC. Consideration was given to how genetic vulnerabilities and environmental stress may interact to place certain siblings at risk. Cross sectional	USA	**Sample:** 57 siblings of children with ASC (Mostly female) **Age target sibs:** 12 – 18 **Age reference sibs:** 14 - 21 (40M/17F) **Reference sib diagnosis**: ASC **Control Group:** No	**Informants:** Mothers	**Measures:** Centre for Epidemiological studies depression scale (CES-D) Revised children's manifest anxiety scale (RCMAS) (completed by siblings) Problem behaviour scale from the scales of independent behaviour-revised (SIB-R)	**Findings:** 36% of siblings reported depressive symptoms at or above the clinical cut-off score of 16 on the CES-D. 8.5% of siblings reported clinically significant anxiety symptoms. This was similar to what would be expected in a community sample. Sisters reported higher level of depressive and anxiety symptoms than brothers, but were comparable to community samples. Brothers reported lower levels of anxiety and depression than the general population. A high level of maternal depression was associated with more depressive and anxiety symptoms in siblings. Having a family history of ASC was associated with more depressive, but not anxiety symptoms. A diathesis stress model was partially supported. Genetic vulnerability to ASC (broad

					autism phenotype) was associated with an increase in depressive and anxious traits but only in the presence of a high number of stressful life events.
Petalas, Hastings, Nash, Dowey & Reilly (2009a) (22) To investigate, using a qualitative methodology, the perceptions and lived experiences of typically developing siblings in middle childhood, who were growing up with a brother with ASC. Cross Sectional (Qualitative)	UK	**Sample:** 8 TD siblings of children with an ASC (3M, 5F) **Age target sibs:** 9 – 12 **Age reference sibs:** 8 to 17 (All boys) **Reference sib diagnosis**: ASC **Control Group:** None	**Informants:** Siblings	**Measures:** Semi-Structured Interviews	**Findings:** The perceived impact of their brothers' disability varied greatly across siblings. Children spoke about the disruption in their daily lives (e.g., sleeping, parental attention), and their brother's peculiar or aggressive behavior. Siblings experienced anger, embarrassment and anxiety as a result of the negative attitudes of strangers and friends. Some siblings felt socially isolated. All siblings were able to identify positive aspects of their experience of having a sibling with ASC. Siblings noted the importance of support from different sources. Siblings reported benefitting from social support, particularly

					when it allowed for open communication No difference in themes across gender.
Petalas, Hastings, Nash, Reilly & Dowey (2012a) (23) **Cross Sectional (Qualitative)**	UK	**Sample:** 12 siblings of children with ASC (6M, 6F) **Age target sibs:** 8 – 17 **Age reference sibs:** 4 – 17 (All boys) **Reference sib diagnosis**: ASC, included children with Asperger **Control Group:** None	**Informants:** Siblings	**Measures:** Semi structured interview	**Findings:** No difference in themes across gender. Siblings reported finding their brothers aggression difficult to manage. Siblings reported feelings of embarrassment, especially around peers. All siblings could identify positive qualities of their brother, and their experience of having a disabled sibling, e.g. increased understanding of diversity. Older siblings worried about the future.
Petalas, Hastings, Nash, Hall, Joannidid & Dowey (2012b) (24) This study investigated how the presence of a	UK	**Sample:** 166 siblings of children with ASC (84M, 82F) **Age target sibs:** 5 to 17 **Age reference sibs:** 5 to 17 (137M, 29F)	**Informants:** Parents	**Measures:** Strengths and Difficulties Questionnaire (SDQ) Hospital Anxiety	**Findings:** Sibling adjustment was associated with the extent of behaviour problems in the child with an ASC and with the extent of the siblings Broad Autism

Broad Autism Phenotype feature in the TD sibling might interact with family environmental risk variables to predict sibling functioning of children with ASC. Cross sectional		**Reference sib diagnosis**: ASC, Aspergers, PDD **Control Group**: None		and Depression Scale (HADS)	Phenotype features. Sibling relationships were more negative when the child with ASC had more behavioral problems and when there was evidence of critical expressed emotion in the family environment. Siblings older than the child with an ASC had lower conflict scores on the SRQ that those that were younger. No other demographics variables had a significant interaction effect.
Petalas, Hasting, Nash, Lloyd & Dowey (2009b) (25) To explore the adjustment of siblings of children with ASC and an ID in contrast to having a sibling with an ID only. Cross sectional	UK	**Sample:** 25 siblings of children with ASC and ID (12M, 13F), 24 siblings of children with ID only **Age target sibs:** 5 -17 **Age reference sibs:** 5 to 19 **Reference sib diagnosis**: ASC and ID **Control Group:** Siblings of children with ID, Normative data	**Informants:** Mothers	**Measures:** Strengths and Difficulties Questionnaire	**Findings:** Siblings of children with ASC and ID were reported by their mothers as having more emotional problems than siblings of children with ID only, and when compared a normative sample. No difference found in conduct problems or total difficulties. Siblings of children with ASC and ID compared to siblings of children with ID only: Emotional Problems 0.56 Conduct Problems 0.12

		Total Problems 0.17 Siblings of children with ASC and ID Vs Normative Sample: Emotional Problems 0.443 Conduct Problems 0.26 Total Problems 0.00 Siblings of children with ID and ASC were more likely to score within the abnormal range for emotional problems and proscoial behaviour problems when compared with siblings of children with ID only and with a normative sample. Behaviour difficulties, except hyperactivity, for siblings of children with autism were relatively stable over 18 months. The following variables had an independent relationships with increased SEB problems in sibling's of children with Autism and ID: increased age of the child with autism, having a brother rather than a sister with autism, being younger than the child with autism and low SES.

Pollard, Barry, Freedman, Kotchick (2013) (26) To examine anxiety levels in TD adolescence with a brother or sister with ASC or DS. To examine the extent to which sibling's relationship quality moderated anxiety levels. Cross sectional	USA	**Sample:** 81 siblings of children with ASC (37M,44F), 38 siblings of children with DS (15M, 23F) **Age target sibs:** 11 to 17 **Age reference sibs:** 11 to 17 (Gender not reported) **Reference sib diagnosis**: ASC, DS **Control Group:** DS and ASC	**Informant:** Parents and Siblings	**Measures:** Multidimensional Anxiety Scale for Children	**Findings:** Siblings of children diagnosed with ASC reported lower levels of overall relationship quality than did siblings of a child with DS. Significant relationship x adjustment effect, for both groups. No significant difference in self-reported anxiety between siblings of children diagnosed with an ASC and siblings of children diagnosed with DS (ES = 0.22). Anxiety was significantly and negatively correlated with overall sibling relationship quality. No association between sibling age, gender or family size and reported levels of anxiety

Roa and Beidel (2009) (27) To investigate the adjustment of siblings of children with high-functioning autism (HFA). Family functioning was also explored. Cross sectional	USA	**Sample:** 7 siblings of children with HFA (3M/4F), 9 sibs of TD children **Age target sibs:** 8 to 16 **Age reference sibs:** 8 to 14 (Male only) **Reference sib diagnosis**: HFA only **Control Group:** Siblings of TD children	**Informants:** Parents	**Measures:** Symptom checklist 90 revised Piers Harris Children's Self Concept Scale 2nd addition Child behaviour checklist (CBCL)	**Findings:** Siblings of children with HFA had higher levels of internalising difficulties but not externalising difficulties. There were no significant difference in self-concept or problem behaviours between the siblings of children with HFA and siblings of children with no disability Parents of children with HFA experience significantly more parenting stress than parents of child with no psychological disorder, which was found to be directly related to characteristics of the children with HFA.
Rodrigue, Geffken, Morgan (1993) (28) To investigate the adjustment of siblings of children with ASC, DS and control children Cross sectional	USA	**Sample:** 19 siblings of children with ASC sibs (10F/9M), 20 sibs of children with DS (10F/10M), 20 sibs of TD children (12F/8M). **Age target sibs:** Mean age 9.45 – 11.05 **Age reference sibs:** Mean ages 10.98 (ASC), 11.93 (DS), 8.1 (TD) **Reference sib diagnosis**:	**Informants:** Siblings, Mothers and Fathers	**Measures:** Perceived Competence Scale for Children (PCSC) or the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (PCSA) (depending on chronological	**Findings:** Siblings of children with an ASC had more internalizing and externalizing behaviour problems than siblings of children with DS (ES = .56/.51) or siblings of TD children (ES = .56/.43); however, the three groups did not differ significantly on measures of perceived self-competence or

		ASC / DS **Control Group:** Siblings of TD children Groups matched on mental age, rather than chronological age.		age) Child behaviour checklist (CBCL)	parents' report of social competence. Although siblings of children with ASC had more internalizing and externalizing behaviour problems their scores on these two dimensions fell within the normative range. Age of sibling and parent's marital satisfaction were associated with sibling's psychological functioning. Gender on the other hand was not associated with adjustment. Older siblings of children with ASC, had higher rates of both internalizing and externalizing behaviours but no difference in perceived competence.
Ross & Cuskelly (2006) (29) To explore the adjustment and coping strategies of siblings of children with an ASC Cross sectional	Australia	**Sample:** 25 siblings of children with ASC (19M/6F) **Age target sibs:** 8-15 **Age reference sibs:** 6-16 (20M,5F) **Reference sib diagnosis**: ASC / Asperger's **Control Group:** None	**Informants:** Parents	**Measures:** Child Behavior Checklist (CBCL)	**Findings:** Mothers reported 40% of TD Sibling's to have significant adjustment difficulties. Siblings of children with ASC were reported to be at an increased risk for developing internalising problems. Mean scores were

					within the average range. Siblings had a good basic knowledge of ASC – although this was not associated with adjustment. Equally coping strategy was not associated with sibling adjustment. Aggression was the most frequently cited stressor in sibling interaction.
Smith and Perry (2004) (30) To examine the effectiveness of a siblings support group for siblings of children with autism Pre and Post Test	Canada	**Sample:** 26 siblings of children with ASC (12M/14F) **Age target sibs:** 6- 16 **Age reference sibs:** 6-16 (gender not reported) **Reference sib diagnosis**: ASC/ PDD **Control Group:** None	**Informant:** Parents	**Measures:** Achenbach Child Behaviour Checklist (CBCL) Piers-Harris Children's Self-Concept Scale	**Findings:** Prior to the intervention 9 siblings (26%) had borderline or clinically significant internalizing difficulties. 5 (20%) had externalizing symptoms in the borderline to clinical range. 4 of the siblings (16%) had both internalizing and externalizing scores in the borderline to clinical range Siblings self concept on the Piers Harris was significantly higher at post-test than at pre-test (ES = 0.50) Sibling's knowledge of disability increased from pre to post test.

Tomeny, Barry & Bader (2012) (31) To explore the extent to which autism symptom severity acted as a moderator of TD sibling adjustment. Cross sectional	USA	**Sample:** 43 siblings of children with an ASC (18M, 25F), 42 TD siblings (33M, 9F) **Age target sibs:** 6- 18 **Age reference sibs:** 8 – 18 (33M, 9F) **Reference sib diagnosis**: ASC **Control Group:** TD Siblings of TD children	**Informant:** Parents	**Measures:** Child Behavior Checklist (CBCL) Children's social behavior questionnaire	**Findings:** Siblings did not significantly differ from control group on measure of internalizing (ES=0.49), Externalizing (ES=0.29) or social problems (ES=0.49). Autism symptom severity did not moderate, or significantly interact with siblings externalizing or internalizing symptoms. Being the TD sibling of a child with ASC was not a risk factor. However there was a relationship between maladjustment in one sibling and maladjustment in another sibling. However this was across both the ASC and control group.
Verte, Roeyers & Buysse (2003) (32) This study investigated the psychological adjustment of siblings of children with an ASC in comparison to	Belgium	**Sample:** 29 siblings of children with ASC (17M/12F), 29 siblings of TD children (17M/12F) **Age target sibs:** 6-16 **Age reference sibs:** 9-16 (28M,1F) **Reference sib diagnosis**:	**Informants:** Parents and Siblings	**Measures:** Child Behaviour Checklist (CBCL) Matson Evaluation of Social skills with youngsters	**Findings:** Siblings of children with an ASC were reported as having more behavior problems, than siblings in the control group. Sibling's aged between 6 and 11 in particular had more behavior problems.

siblings of normally developing children. Cross sectional	HFA only **Control Group:** TD siblings of TD children	(MESSY) Self description Questionnaire 1 & 11 (SDQ-I & SDQ-II)	Siblings aged 6 to 11 had more internalizing and externalizing problems. However the mean score did not fall into the clinical or subclinical range. Sister of children with an ASC aged 12 to 16 had a more positive self-concept and higher social competence than sisters of the control group. CBCL Total Problems (6-11 HFA girls to TD girls): ES = 2.088 (6- 11 HFA boys to TD boys): ES = 2.651 (12-16 HFA girls to TD girls): ES = 0.946 (12-16 HFA boys to TD boys): ES = 0.044 CBCL Externalizing: 6-11 HFA girls to TD girls): ES = 1.456 (6- 11 HFA boys to TD boys): ES = 2.447 (12-16 HFA girls to TD girls): ES = 1.093 (12-16 HFA boys to TD boys):

					ES =0.568 CBCL Internalizing: (6-11 HFA girls to TD girls): ES = 2.00 (6- 11 HFA boys to TD boys): ES = 2.087 (12-16 HFA girls to TD girls): ES = 0.36 (12-16 HFA boys to TD boys): ES = 0.448
Wolf, Fisman, Ellison & Freeman (1998) (33) To examine siblings perceptions of differential parental treatment in families of children with PDD, DS and nondisabled children, over a 3 year period Longitudinal Cross sectional	Canada	**Sample:** 46 siblings of children with PDD (18M/28F), 45 siblings of children with DS 17M/28F), 46 siblings of TD children (18M/28F). **Age target sibs:** 8 – 16 (54M/84F) **Age reference sibs:** 4 – 18 Child with DS: 21M/24F Child with PDD: 38M/8F **Reference sib diagnosis**: DS, PDD, ASC **Control Group:** Siblings of TD children	**Informants:** Parents and Teachers	**Measures:** The Survey Diagnostic Instrument adapted from the Child Behavior Checklist (CBCL) The self-perception profile for children	**Findings:** Siblings of children with PDD were reported at time 1 and 2 to have increased levels of internalizing and externalizing problems, as reported by parents. At time 2 teachers also identified increased externalizing difficulties. Siblings of children with DS were reported by parents and teachers to have increased internalizing difficulties at time 2 only. For both the siblings of children with PDD and siblings of children with DS, adjustment

			difficulties relating to perceived parental differential treatment became more evidence over a 3 year period. For siblings of children with PDD, the perception that they are preferred over their disabled sibling was predictive of adjustment difficulties. Conversely, for the siblings of children with DS it is the perception that their disabled sibling is preferred, particularly over time, that was associated with internalizing adjustment difficulties. Social support (especially over time) had a positive effect on all siblings, including controls.

Note. ASC autism spectrum disorder; DS Down syndrome; PDD-NOS pervasive developmental disorder – not otherwise specified; TD typically developing children, M Male, F Female, SEB Social Emotional Behavioural adjustment.

Appendix B: List of search terms used in the systematic review

Searches were conducted in each database (PsycInfo via Ebsco; 1887-2013 and Web of Science via Web of Knowledge; 1950-2013). Original search terms were generated by the researcher with further terms added based on keywords from relevant articles found during the search process. All search terms are reported below according to the database in which they were entered. Following the search terms being entered, limited were applied in order to retrieve studies which met the inclusion criteria, and for example 'peer reviewed journal 'and 'English language'.

1. **PsycInfo (via Ebsco; 1887-2013):** All search results from the search terms below were filtered by Age: school age (6-12 yrs), adolescence (13-17 yrs), Type of journal; 'peer reviewed', 'exclude dissertations' and Language; 'English language'.

Psychological Stress *or* Mental Health *or* Self Concept *or* Self Perceptions *or* Stress *or* Well Being *or* School Adjustment *or* Behavior Problems *or* Resilience(Psychological) *or* Coping Behavior *or* Academic Achievement *or* Educational Attainment Level *or* Adjustment *or* Social Adjustment *or*	and	Siblings *or* Sibling Relations *or* Family *or* Family Relations *or* Brothers *or* Sisters *or*	and	Developmental Disabilities *or* Disabilities *or* Down's Syndrome *or* Autism *or* Pervasive Developmental Disorders *or* Learning Disabilities *or* Aspergers Syndrome *or*

2. **Web of Science (via Web of Knowledge; 1950-2013):** All search results from the search terms below were filtered by type of publication: 'peer reviewed' and 'article,' and language; 'English.'

The Search was further refined by excluding Web of Science Categories which were considered not relevant: 'Endocrinology Metabolism', 'Women Studies', 'Research Methods', 'Biochemical Research Methods', 'Urban Studies', 'Biology', 'Chemistry', 'Medical', 'Chemistry Multidisciplinary', 'Communication', 'Toxicology', 'Developmental Biology', 'Biochemistry Molecular Biology', 'Environmental Studies', 'Genetic Heredity', 'Dentistry Oral Surgery Medicine', 'Gastroenterology Hepatology', 'Neurosciences', 'Opthalmology', 'Gerontology', 'Health Care Sciences Services,' 'Hematology,' 'Marine Freshwater Biology,' 'Otorhinolaryngology,' 'Nursing,' 'Pathology Physiology,' 'Public Environmental Occupational Health,' 'Obstetrics,' 'Gynecology,' 'Plant Sciences,' 'Radiology,' 'Nuclear Medicine,' 'Medical,' 'Imaging or Audiology,' 'Speech Language Pathology', 'Reproductive Biology', 'Linguistics,' 'Agricultural Dairy,' 'Animal Science,' 'Anesthesiology,' 'Surgery,' and 'Anthropology'.

Expressed Emotion *or* Emotion Problems *or* Adjustment *or* Behavioural Adjustment *or* Psychological Adjustment *or* Social Adjustment / Functioning *or* Psychological Impact *or* Behaviour Problems *or* Experience *or* Stress *or* Self Perception *or* School *or* School Impact	*and*	Siblings *or* Sibling Relations *or* Brothers *or* Sisters *or* Sibling Adjustment	*and*	Developmental Disabilities *or* Disabilities *or* Down-Syndrome *or* Autism *or* Pervasive Developmental Disorders *or* Autism Spectrum Disorder *or* Learning Disabilities *or* Aspergers Syndrome *or* Cognitive Disabilities *or* Disabled-Children *or* Impairment

Appendix C: Summary of Inclusion/ Exclusion Criteria

Inclusion/Exclusion Criteria Used for the Screening of Studies

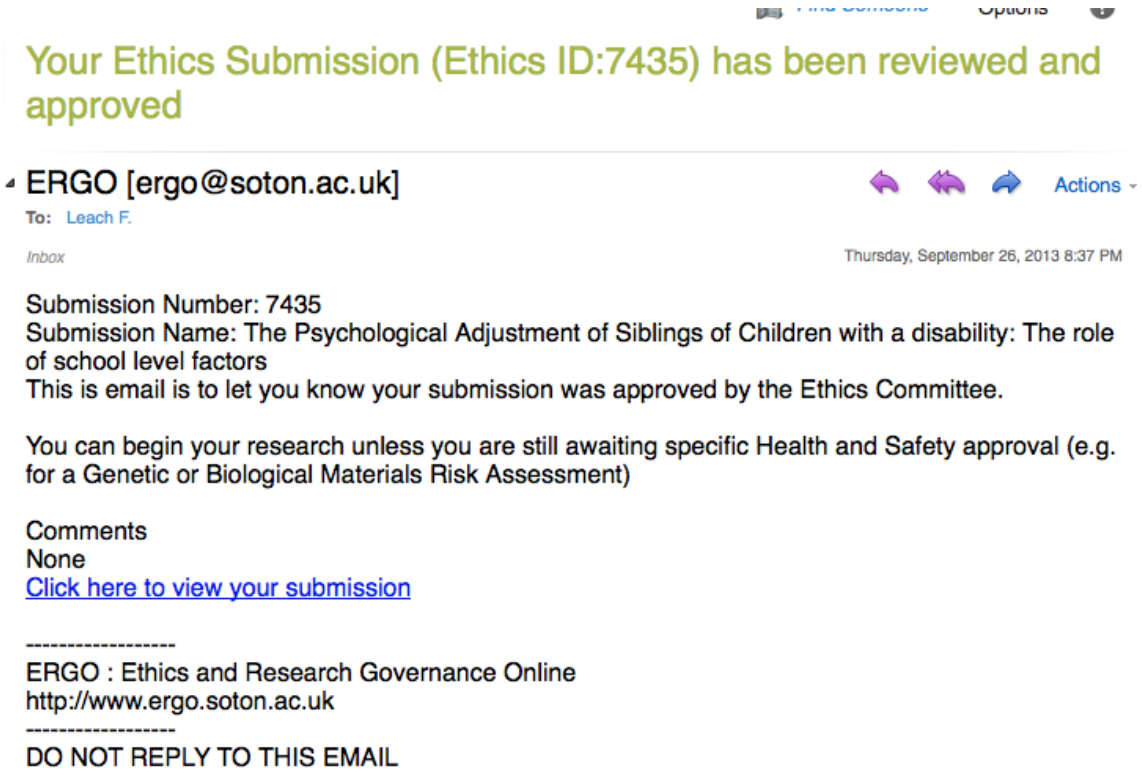
Study Item	Inclusion Criteria	Exclusion Criteria
Participants: **Target Siblings**	Aged 4 to 19	Pre-school children
Participants: **Reference Siblings**	Aged 4 to 21	Pre-school children
Outcomes	Studies that explore the social, emotional or behavioural outcomes of siblings	Studies that do not include social, emotional or behaviour outcomes for siblings.
	Factors which are related to adjustment	Studies that do not consider how factors (e.g. relationships) related to sibling adjustment
Language	Published in English	Published in any language other than English.
Type of research	Research that is primary in nature. Published studies. Peer reviewed	Research that is not primary in nature e.g. discussion or review of studies. Unpublished dissertations Case studies
Date	Study published after 1978	Study published before 1978
Country of origin	North America, Europe, Australia	Studies conducted in a country other than North America, Europe or Australia

Appendix D: Reasons for excluding papers for which full text was obtained

All titles and abstracts of the papers identified from electronic database were screened. 73 papers were identified as relevant and retrieved in full text. In addition 13 articles were retrieved in full following a hand search (e.g. searching the reference lists of relevant articles), resulting in a total of 86 full tests. 53 papers were excluded for the following reasons. In incidence in which papers were excluded for more than one of the listed reasons, the first reason reported in the full text is the reason given.

1. Papers in which the typically developing child or the child with a disability did not fit the inclusion criteria according to age (n = 3)
2. Papers presenting a review of research rather than original research (n= 6)
3. Papers in which the country from which participants were recruited did not fit inclusion criteria (n=2)
4. Papers in which the type of disability was not clearly defined or the outcomes of siblings of children with ASC and/ or DS was mixed with the outcomes of siblings of other disabilities (n=31)
5. Studies in which the child with a disability was not placed in the family home full time (n=5)
6. Studies that did not measure social, emotional and/ or behavioural adjustment of typically developing siblings but focused on relationships or coping style (n=6)

Appendix E: Ethical Approval



Your Ethics Submission (Ethics ID:7435) has been reviewed and approved

ERGO [ergo@soton.ac.uk]

Actions

To: Leach F.

Inbox

Thursday, September 26, 2013 8:37 PM

Submission Number: 7435
Submission Name: The Psychological Adjustment of Siblings of Children with a disability: The role of school level factors
This is email is to let you know your submission was approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments
None
Click here to view your submission

ERGO : Ethics and Research Governance Online
http://www.ergo.soton.ac.uk

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Appendix F: Loneliness and Social Dissatisfaction in Young Children Questionnaire

Loneliness and Social Dissatisfaction in Young Children

1. Is it easy for you to make new friends at school?
2. Do you like to read?*
3. Do you have other kids to talk to at school?
4. Are you good at working with other kids at school?
5. Do you watch TV a lot?*
6. Is it hard for you to make friends at school?+
7. Do you like school?*
8. Do you have lots of friends at school?
9. Do you feel alone at school?+
10. Can you find a friend when you need one?
11. Do you play sports a lot?*
12. Is it hard to get kids in school to like you?+
13. Do you like science?*
14. Do you have kids to play with at school?
15. Do you like music?*
16. Do you get along with other kids at school?
17. Do you feel left out of things at school?+
18. Are there kids you can go to when you need help in school?
19. Do you like to paint and draw?*
20. Is it hard for you to get along with other kids at school?+**
21. Are you lonely at school?+
22. Do the kids at school like you?
23. Do you like playing card games?*
24. Do you have friends at school?

+ Items for which response order was reversed in scoring.
* Filler items, focusing on hobby or interest items.
** Due to a clerical error, this item was not administered in the Cassidy and Asher (1992) study.
from Cassidy, J., & Asher, S. R. (1992). Loneliness and peer relations in young children. Child Development, 63, 350-365.

Appendix G: Differential Parenting Index Questionnaire

Me and My Parents

Instructions: Compared to your brother or sister with a disability, how do you feel your parents treat you? Please rate this on a scale from 1-5, 1 = Exactly the same and 5 = Very Different.

1 2 3 4 5

Exactly the same Very different

On a scale from 1-5 please show me how you feel about this? 1 = Very unhappy and 5 = Very happy.

1 2 3 4 5

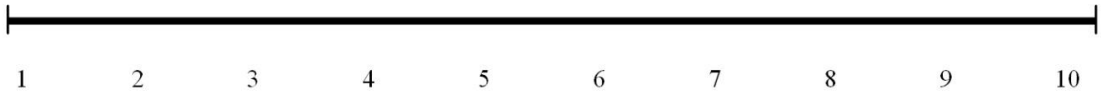
Unhappy Ok Happy

]

Appendix H: Knowledge of Disability Questionnaire

My Knowledge of Disability

Instructions: On a scale from 0-10, please circle a number showing how much you feel you know/understand about your brother or sister's disability (1 = None and 10 = The most I can know/understand).



Appendix I: Authorisation from Questionnaire Authors

Inbox Saturday, March 09, 2013 1:33 A

Hi
Sure. I am cc'ing Ellen Lockwood who can send you what you need.
Good luck with your work.

Best,
JCassidy

Leach F.

Sent Items Friday, March 08, 2013 3:25 F

Dear Jude,

I am a student at the University of Southampton (UK) currently studying for my doctorate in Educational Psychology. I am starting to work on my thesis which is looking at the adjustment of siblings of children with disabilities. In particular I am interested in exploring school factors which may act as a risk or resilient factor.This includes looking at peer relationships. In some of the research I have been reading your measure; The Loneliness and Social Dissatisfaction Questionnaire Social Support Scale for Children has been used. I would be really interested in looking at, and with your permission using this scale in my research? Thank you for considering this request.

Kind Regards,

Fran Leach

Doctorate in Educational Psychology - Thesis

Susana Gavidia-Payne [susana.gavidia-payne@rmit.e... Actions

To: Leach F.

Cc: Kate Emily Davis [kate.davis@rmit.edu.au]

Inbox Monday, March 11, 2013 1:30 AM

Dear Fran,

Thank you for your email and interest in using some of the measures incorporated into Kate Davis' thesis under my supervision.

Here is some information about the measures:
1. Knowledge of disability scale. The knowledge of disability scale was developed by us and is an analog scale that is rated by both the parent/primary caregiver and sibling.

On a scale from 0-10, please circle how much you feel your typically developing child knows/understands about his/her brother or sister's disability (0 = None and 10 = The most I feel he/she can know/understand).

On a scale from 0-10, please circle how much you feel you know/understand about your brother or sister's disability (0 = None and 10 = As much as I can know/understand).

2. Differential parenting index. These items were developed/adapted based on items by McHale and Gamble (1989). An analog scale was used and items were completed by both the parent/primary caregiver and sibling.

In comparison to your child with a disability, how do you feel you treat your child without a disability? Please rate this on a scale from 1-5 from exactly the same to very different (1 = Exactly the same and 5 = Very Different).

On a scale from 1-5 please rate how you believe your typically developing child feels about this treatment? (1 = Very unhappy and 5 = Very happy).

In comparison to your brother or sister with a disability, how do you feel your parents treat you? Please rate this on a scale from 1-5 from exactly the same to very different.

On a scale from 1-5 please rate how you feel about this? (1 = Very unhappy and 5 = Very happy).

Exploring school factors and their influence on the adjustment of siblings of children with disabilities sounds like a very interesting project. We have been conducting research over the past 2 years on resilience (not necessarily with siblings), and have been exploring factors such as the influence of the student-teacher relationship (using the student-teacher relationship scale, developed by Painta) on children's adjustment and well-being. Extending school factors to siblings of children with disabilities sounds exciting. I have CC Kate into this email (kate.davis@rmit.edu.au) should you have any questions for us in the future. We wish you all the best with your research.

Appendix J: Invitation letters to schools, centres and services

Title of Project: The adjustment of siblings of children with disabilities: The role of school level factors

Dear ……

My name is Fran Leach and I am a Trainee Educational Psychologist from the University of Southampton. I am currently conducting research, which aims to gain a better understanding of the experiences of siblings who are growing up with a brother or sister with a disability.

I am looking to carry out my research with siblings of children with Down syndrome or Autistic Spectrum Condition (ASC) and their families and am hoping that your school/centre/ service may be able to assist me in recruiting participants.

This study asks parents and siblings of disabled children to complete a questionnaire, which will take approximately 20-30 minutes. I have enclosed a copy of the 'letter of invitation,' 'Parent information sheet' and 'Sibling information sheet' and a copy of the questionnaire booklets which parents and siblings will be asked to complete. This will provide you with more information about the study.

If you agreed for your school/ centre/ service to assist in recruiting participants, you would be asked to distribute 'Letters of Invitation' and consent forms to families who have a child with Down syndrome or ASC. This can be either in person/ via post or electronically. You would not be asked to collect any data or provide the contact details of any families.

I will follow up this letter with a phone call within the next week to discuss the possibility of recruiting families from your school/ centre/ service.

In the meantime, if you have any questions relating to this study please do not hesitate to contact me directly via email (see below).

Your sincerely,

Appendix K: Parent Invitation Letter

Dear Parents/ Guardian,

My name is Fran Leach and I am a Trainee Educational Psychologist from the University of Southampton. I am writing to seek your participation in a research project to assist us in understanding how siblings are influenced by growing up with a brother or sister with Down Syndrome or Autism Spectrum Condition (ASC). Your opinions and experiences are important and will help us to identify ways to support siblings of children with disabilities. In particular this study will consider ways in which schools can support siblings.

I am specifically looking to carry out my research with siblings of children with Down syndrome or ASC. To participate in this study, typically developing siblings must be aged 7 to 11 attending a day primary school. They must live in the same household as their disabled sibling, and have no disability. Only one sibling per family may participate. The sibling with Down syndrome or ASC needs to be aged between 5 and 16 years and attending school as a day pupil. Children without a disabled sibling will also be asked to participate to form a comparison control group.

If you have more than one typically developing sibling, both would be welcome to participate in the study, and would each be sent a separate questionnaire and certificate on completion.

The data gathering would involve both the typically developing sibling and one of their parents completing a series of questionnaires, either as a paper booklet or online. It is estimated that this will take between 20 and 30 minutes for both parents and siblings.

What happens next?

If you are interested in participating in this study please read the attached information sheet, and discuss with your typically developing child this study – including showing them the sibling information sheet. If both you and your sibling are happy to participate please sign the consent form and ask your son/daughter to sign the sibling assent form. Please return signed forms to:

Appendix L: Parent Information Letter

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Information sheet for parents/ guardians

Project Title: The Adjustment of Siblings of Children with a Disability: The role of school level factors

Researcher: Fran Leach supervised by Dr Donna McCann

I would like to invite you and your child to take part in a research study. Please read the following information sheet carefully. Should you have any further questions please feel free to contact me. Should you be happy to participate in this study please discuss the content of this information sheet with your typically developing son or daughter. You may also wish to discuss this study with your son or daughter with Down syndrome or Autism Spectrum Condition (ASC) should you feel this is appropriate.

Who is involved in this research project?

This research is being conducted by Fran Leach a Trainee Educational Psychologist from the University of Southampton. Parents and typically developing siblings of children with Down syndrome or ASC have been invited to take part in the study. Parents and siblings of children without a disability have also been invited to take part in this study, to form a comparison group.

What is the project about? What are the questions being addressed?

The aim of this research is to gain a better understanding of the experiences of siblings of growing up with a brother or sister with a disability. In particular this study considers the role of school factors (e.g. relationship with teachers) in sibling's wellbeing.

It is anticipated that the information obtained from this study will help identify how to best support siblings of children with a disability and enhance their psychological wellbeing.

Why have you been approached?

This study is looking to recruit typically developing siblings of children with ASC or Down syndrome, aged 7 to 11 attending a day primary school, alongside one of their parents. In order to participate in this study, the typically developing sibling must live in the same household as their disabled sibling, and have no special needs. Disabled siblings must be aged between 5 and 16 and attend a day school.

If you have more than one typically developing sibling, both are welcome to participate in the study. However separate questionnaires will need to be completed by each sibling.

If I agree to participate, what will I be required to do?

Parents, if you agree to take part in this research you will be required to complete a questionnaire, either online or via a postal questionnaire. This questionnaire will ask you about your child who has Down syndrome or ASC, your typically developing child, your general wellbeing, and the wellbeing of your family.

If your typically developing child agrees to take part in this research they will also be required to answer some questions about their experience of growing up with a brother or sister with a disability, their general wellbeing and their experiences at school including peer and teacher relationships. Again this can be either online or via a postal questionnaire. Parents may read the sibling questionnaire prior to giving it to their child to ensure they are happy for their child to continue.

For both parents and siblings it is anticipated that the questionnaires will take approximately 20 to 30 minutes to complete.

What are the risks associated with participation.

Whilst there are no anticipated risks, we know that for some parents and siblings talking about their disabled child/ sibling may elicit feelings of distress or anxiety. Should any participate experience distress at any time during the study they are free to withdraw from the study without having to give a reason and without their rights being affected in any way.

What are benefits associated with participation?

There are no direct benefits from participating in this study. However, findings from this research will help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life. A brief report of findings will be distributed to you at the completion of the study.

What will happen to the information I provide?

All the information you provide will be treated confidentially. Only the researcher and supervisor will have access to the information in its raw form. Additionally, this study will use linked anonymity e.g. whilst data will not be collected anonymously it will be anonymised at the first instance. This will include the questionnaire being labelled with a randomly generated ID codes which correspond to a participants' name. This list of participant's names and their respective corresponding ID codes will be kept separately to the data and questionnaires at all times. Research data will be kept on a password protected computer for a period of five years before being destroyed. The final report will only contain group data and may appear in a journal article in the future.

What are my rights as a participant?

Participation in the study is voluntary for both you and your child. Both you and your child have the right to withdraw from the study at any time, without providing an explanation.

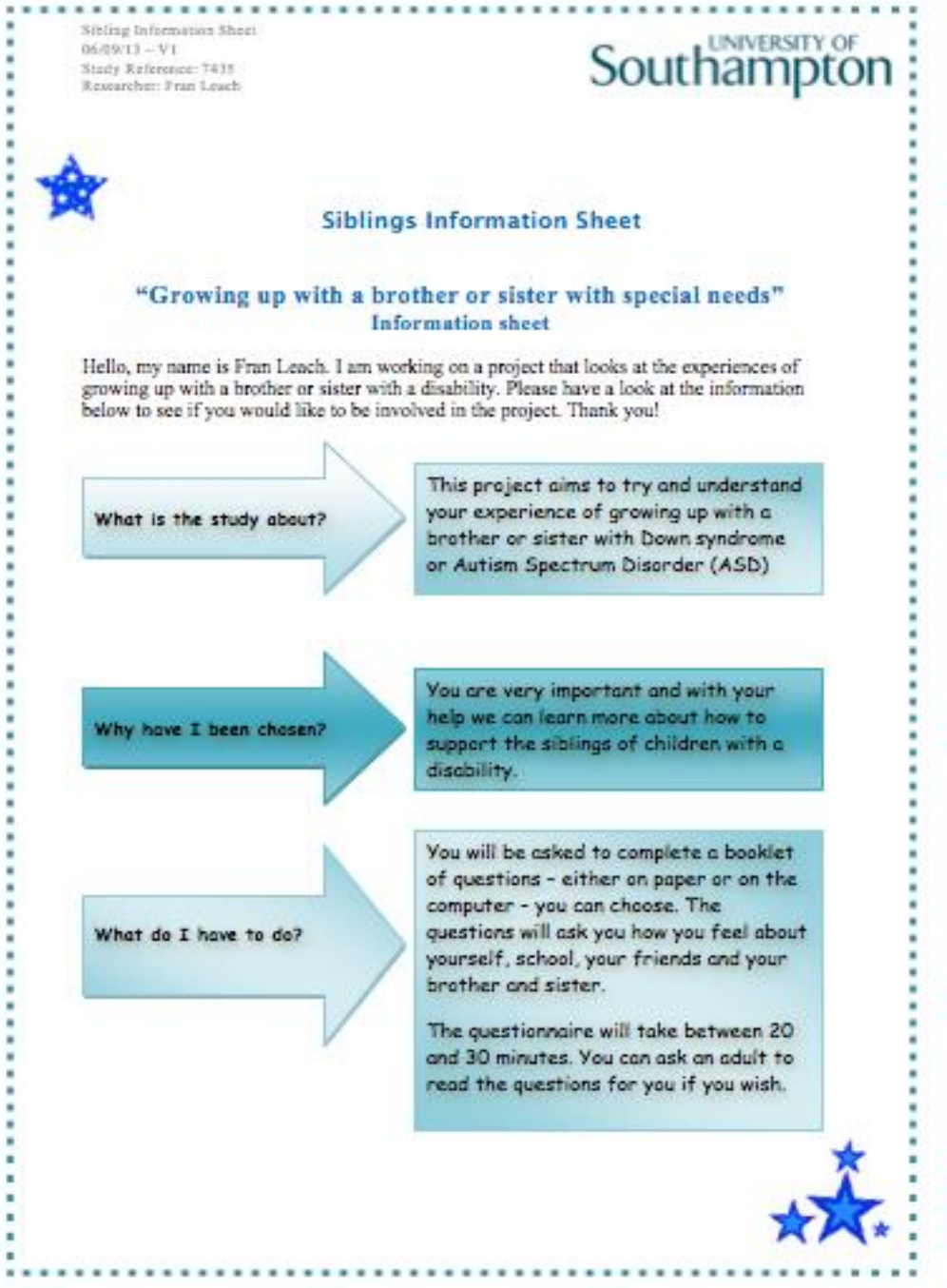
Who has reviewed this study?

This study has been reviewed and approved by the University of Southampton, School of Psychology Ethics Committee. All necessary safeguarding checks and references have been successfully completed.

Who should I contact if I have any questions?

We hope that the experience will be informative and valuable to you. If you have any questions please feel free to email Fran Leach (email fl7g11@soton.ac.uk). If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, Southampton, SO17 1BJ. (Tel: 02380 594663) (Email: slb1n10@soton.ac.uk).

Appendix M: Sibling Information Sheet



Sibling Information Sheet
06/09/13 – V1
Study Reference: 7435
Researcher: Fran Leach

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Siblings Information Sheet

"Growing up with a brother or sister with special needs"
Information sheet

Hello, my name is Fran Leach. I am working on a project that looks at the experiences of growing up with a brother or sister with a disability. Please have a look at the information below to see if you would like to be involved in the project. Thank you!

What is the study about?

This project aims to try and understand your experience of growing up with a brother or sister with Down syndrome or Autism Spectrum Disorder (ASD)

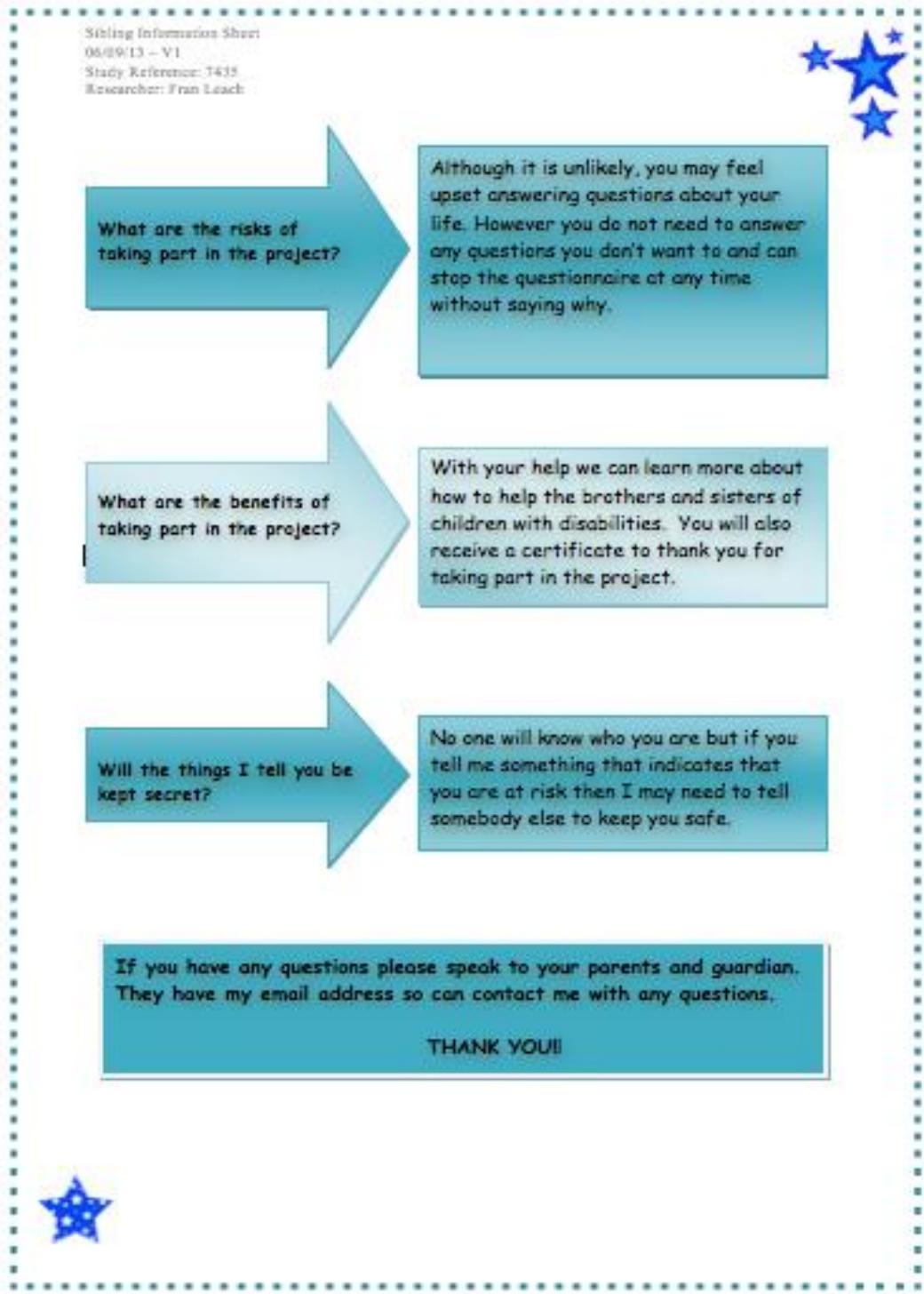
Why have I been chosen?

You are very important and with your help we can learn more about how to support the siblings of children with a disability.

What do I have to do?

You will be asked to complete a booklet of questions – either on paper or on the computer – you can choose. The questions will ask you how you feel about yourself, school, your friends and your brother and sister.

The questionnaire will take between 20 and 30 minutes. You can ask an adult to read the questions for you if you wish.


Sibling Information Sheet
06/09/13 – V1
Study Reference: 7435
Researcher: Fran Leach
What are the risks of taking part in the project?
Although it is unlikely, you may feel upset answering questions about your life. However you do not need to answer any questions you don't want to and can stop the questionnaire at any time without saying why.
What are the benefits of taking part in the project?
With your help we can learn more about how to help the brothers and sisters of children with disabilities. You will also receive a certificate to thank you for taking part in the project.
Will the things I tell you be kept secret?
No one will know who you are but if you tell me something that indicates that you are at risk then I may need to tell somebody else to keep you safe.
If you have any questions please speak to your parents and guardian. They have my email address so can contact me with any questions.
THANK YOU!!

Appendix N: Parent Debrief Letter

Dear Parents,

I am writing to thank you for your cooperation regarding the recent research project that you and your child participated in, titled: The Adjustment of Siblings of Children with a Disability: The role of school level factors.

The project's aim was to investigate the impact on siblings of having a brother or sister with Down syndrome or Autism Spectrum Disorder. In particular the study considered how school factors (e.g. relationships with teachers and peers) impact on sibling's wellbeing. It is hoped that findings from this research will help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life.

During the project parents and siblings of children without Down and Syndrome or Autism Spectrum Disorder also participated in order to form a comparison group.

I would like to thank you and your child for your involvement in the project. I hope you found the questionnaires interesting.

If you have any questions about the project please feel free to contact me using the details provided below. If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, Southampton, SO17 1BJ (Tel: 02380 594663, email slb1n10@soton.ac.uk)

Yours sincerely,

Appendix O: Sibling Debrief Sheet

Sibling Debrief Sheet
04/08/13 – V1
Study Reference: 7435
Researcher: Fran Leach

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Sibling Debrief Sheet

Dear (Enter Childs Name),

Thank you for helping with my project. I hope that you enjoyed completing the questionnaires and sharing your experiences.

I wanted to hear about your experiences of growing up with a brother or sister with a disability – thank you for sharing this information. I have included a certificate to thank you and congratulate you for taking part in the project.

If you have any questions about the project please talk to your parents or guardian who will know how to contact me.

Thank you

Fran

Appendix P: Sibling Certificate

Certificate

Awarded to

.....

For participating and completing the project 'Growing up with a brother or sister with special needs: My experiences'

Signed .....

Appendix Q: Ethics Application

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ERGO application form – Ethics form

All mandatory fields are marked (M*). Applications without mandatory fields completed are likely to be rejected by reviewers. Other fields are marked "if applicable". Help text is provided, where appropriate, in italics after each question.

1. APPLICANT DETAILS

1.1 (M*) Applicant name:	Francesca Leach
1.2 Supervisor (if applicable):	Dr Donna Mccann
1.3 Other researchers/collaborators (if applicable): *Name, address, email, telephone*	N/A

2. STUDY DETAILS

2.1 (M*) Title of study:	The Psychological Adjustment of Siblings of Children with a disability: The role of school level factors
2.2 (M*) Type of study (*e.g. Undergraduate, Doctorate, Masters, Staff*):	Doctorate
2.3 i) (M*) Proposed start date:	03/09/2013
2.3 ii) (M*) Proposed end date:	25/07/2014

2.4 (M*) What are the aims and objectives of this study?
Research has suggested that siblings adjust to having a brother or sister with a disability in diverse ways (Giallo & Gavidia-Payne, 2005). Whilst most are well adjusted (Rossiter & Sharpe, 2001) others are vulnerable to poor psychological wellbeing (e.g., Hastings, 2003). Sibling, family and disability factors have been found to influence sibling adjustment. However, factors in the wider community, and specifically school level factors have received little empirical consideration. This study therefore aims to explore the impact of school level factors on the psychological adjustment of siblings of children with Down syndrome or Autism Spectrum Disorder (ASD). Globally, this study aims to answer the following question: "To what extent do school factors explain the adjustment differences in siblings of children with a disability?"

2.5 (M*) Background to study (*a brief rationale for conducting the study*):
This study aims to use a questionnaire (postal and online) to investigate the influence of school level factors on sibling's of disabled children psychological adjustment. At a practical level, if factors which mediate mental health problems in siblings can be identified and are viable areas of intervention, there is the potential to promote positive change. This will allow for advances in the evidence based intervention tools available to work with siblings.

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The following school level factors will be considered;
- Sense of School Belonging
- Peer relationship
- Teacher relationship.

These factors have been identified within the risk and resilience literature as potential factors which may influence sibling adjustment.

2.6 (M*) Key research question (*Specify hypothesis if applicable*):

Research Questions

Study 1.
Aim 1: Examine direct effects of school level factors on sibling's psychological adjustment.
RQ1 – Is there a significant difference between the wellbeing of siblings of disabled children and a control group? b) Does this differ by disability group?
RQ2 – Is there a significant difference between school level factors (e.g., SOSB, and teacher relationship) in siblings of disabled children and a control group? b) Does this differ by disability group?
RQ3- To what extent is each of the school level factors associated with the outcomes of siblings of disabled children? b) Does this differ by disability group?
RQ4 – To what extent do school level factors explain the variance in outcomes of siblings of disabled children? B) Does this differ by disability group?

Study 2.
Aim 2: Examine effects of siblings, family, disability and school Factors on sibling's psychological adjustment.
RQ5 – To what extent are the siblings individual level variables (e.g., knowledge of disability) related to sibling adjustment (e.g., internalizing and externalizing symptoms)? Does this differ by disability?
RQ5 – To what extent are family level variables (e.g., parental wellbeing) related to sibling adjustment? Does this differ by disability?
RQ6 – To what extent are demographic variables (e.g., SES) related to sibling adjustment? Does this differ by disability?
RQ7– What are the predictors of sibling adjustment across individual, family and wider social community level factors (including school variables). What proportion of variance do these factors explain? Does this differ by disability?

Research Hypotheses

Study 1.
- Siblings of disabled children will report higher levels of adjustment difficulties, than the normative population. This will be higher for siblings of children with ASD than Down Syndrome.
- Siblings of disabled children will report a lower SOSB and less satisfactory peer and teacher relationships than the control group.
- School level factors (positive SOSB, good peer relationships, and supportive teacher relationship) will be associated with better adjustment (fewer symptoms of internalizing and externalizing problems) for all groups.
- School level factors will explain some of the variance in outcomes of siblings of disabled children.

Study 2.
- Individual level factors will correlate with sibling adjustment with knowledge of disability and parental treatement associated with fewer symptoms of internalizing and externalizing problems.

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- Family level factors will be associated with sibling adjustment with poor parental wellbeing and parental loneliness associated with an increase in internalising and externalizing problems.
- A combination of individual, school, family and wider community factors will provide a better prediction of sibling adjustment, than any layer of factors alone.
- There will be a difference between the groups in identification of risk and protective factors.

2.7 (M*) Study design (*Give a **brief** outline of basic study design*)
Outline what approach is being used, why certain methods have been chosen.

In order to address the aforementioned research questions, the study will use a questionnaire design. Parents and siblings of disabled children will be required to complete either a postal or electronic questionnaire (depending on what is most convenient for the participants). All questionnaires, with the exception of the demograhics section of the parent questionnaire are either standardised or have been used with the current age group.

3. SAMPLE AND SETTING

3.1 (M*) How are participants to be *approached*? *Give details of what you will do if recruitment is insufficient. If participants will be accessed through a third party (e.g. children accessed via a school) state if you have permission to contact them and **upload any letters of agreement to your submission in ERGO**.*

In order to recruit participant's organisations which support children with Down syndrome or Autistic Spectrum Disorder will be approached.

1. Initial introduction letters will be sent to schools/ centres and services which support disabled children and their families (e.g., special needs schools, sibling support groups and charities). This will ask services to give permission for recruitment of families from their organisation. (See attachment - letter to schools, centre and services). Schools/ centres and services will also be sent copies of the parent and sibling information sheet and copies of the questionnaires in order for them to gain a better understanding of the study.

2. Letters to organisations will be followed by a phone call, one week after the letter has been sent.

3. Organisation which agree to assist in recruitment will be asked to sign a consent form (schools/centres/ services consent form).

4. Organisation which agree to assist in recruitment will be asked to distribute 'letters of invitation,' consent forms and parent/sibling information sheets to parents and siblings (see attachment). Organisation which are not happy to do this, will be asked if they are willing to place an add on their website, giving researchers details. Services will be provided with paper and electronic version of letters of invitations according to preference.

5. Families who respond to the 'letter of invitations' or online advert will be sent a full questionnaire pack or a link to online questionnaire depending on preference.

3.2 (M*) Who are the proposed sample and where are they from (e.g. fellow students, club members)? *List inclusion/exclusion criteria if applicable. NB The University does not condone the use of 'blanket emails' for contacting potential*

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participants (i.e. fellow staff and/or students).

It is usually advised to ensure groups of students/staff have given prior permission to be contacted in this way, or to use of a third party to pass on these requests. This is because there is a potential to take advantage of the access to 'group emails' and the relationship with colleagues and subordinates; we therefore generally do not support this method of approach.

If this is the only way to access a chosen cohort, a reasonable compromise is to obtain explicit approval from the Faculty Ethics Committee (FEC) and also from a senior member of the Faculty in case of complaint.

The present thesis will use a purposive sample, made of the follow groups:

- Siblings of children with Down syndrome
- Siblings of children with ASD
- Siblings of children with no disability (control group)

This study is looking to recruit typically developing siblings of children with ASD or Down syndrome. Siblings must be aged 7 to 11 and attend a day primary school. In order to participate in this study, the typically developing sibling must live in the same household as their disabled sibling, and have no identified disability. Disabled siblings must be aged between 5 and 16 and attend a day school.

If there are more than one typically developing sibling in a family then the siblings closest in age will be asked to participate.
For each sibling participant, a parent will also be required to partake.

Organisations which support children with Down syndrome or Autistic Spectrum Disorder will be approached e.g., Downs Education.

3.3 (M*) Describe the relationship between researcher and sample (*Describe any relationship e.g. teacher, friend, boss, clinician, etc.*)

The researcher has no relationship with the sample. However it is possible that in my role as a trainee Educational Psychologist I may work with some parents and siblings who have volunteered to participate in the study - however this would be very unlikely.

3.4 (M*) Describe how you will ensure that fully informed consent is being given: (*include how long participants have to decide whether to take part*)

All participants will be asked to sign a consent form prior to being sent the questionnaire booklets/ online questionnaire. Please see the attached consent form and child ascent form.

4. RESEARCH PROCEDURES, INTERVENTIONS AND MEASUREMENTS

4.1 (M*) Give a brief account of the procedure as experienced by the participant *(Make clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear total demands made on participants, including time and travel).* ***Upload any copies of questionnaires and interview schedules to your submission in ERGO.***

1. Participants will be sent/ emailed or given an 'Invitation pack' by a service

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they already access. This will include a 'letter of invitation' which briefly outlines the study. If parents are interested in participating in the study they are encouraged to read the more detailed information sheet which will also be included in the 'invitation pack.' Following this parents who wish to participate are asked to discuss the study with their typically developing child. This includes showing and discussing the 'sibling information sheet', which is included in the 'invitation pack', with their son/ daughter. Where parents feel appropriate they are encouraged to also discuss the study with their disabled sibling.

2. Once parents and siblings have read the information sheets should they wish to continue they are asked to sign the consent forms/ ascent forms (included in the invitation pack). Parents are asked to return these signed forms to the researcher via email or post as directed on the letter of invitation. This form asks participants to indicate how they would like to complete the questionnaire (on-line/paper version).

3. Once the researcher has received the consent form participants who have selected to complete a paper version of the questionnaire will be sent the questionnaire and a stamped and addressed envelope by which to return the questionnaire. Each questionnaire will have a randomly generated ID number on the top. A record of names and the ID number of the sent questionnaire will be kept on a password protect file on the computer. The parent and typically developing child/children will have the same ID numbers but with a character added to distinguish between parents and siblings(s).

4. Participants, who have selected to complete the questionnaire online, will be sent a link to the questionnaire and a unique code which will allow them to access the questionnaire. Participants unique codes will give them access to a questionnaire already linked to their unique ID number. A record of unique ID numbers and names will be stored on a password protected file on the computer. Unique ID numbers will be generated once a consent form has been received.

5. Once questionnaires have been received, participants will be sent a debrief sheet (parent and sibling) alongside a certificate of participation for siblings.

During piloting both the parents and sibling questionnaire has taken between 20 and 30 minutes.

All questionnaires have been used in previous studies with the current age range. Permission has been received from all authors to use questionnaires in the current research project.

5. STUDY MANAGEMENT

5.1 (M*) State any potential for psychological or physical discomfort and/or distress?

It is not anticipated that the participants of this study will experience any discomfort or any adverse effects. However some participants may find it difficult or experience discomfort when talking about their wellbeing, their child's disability or the impact on their typically developing sibling. Participants will be reminded of their right to withdraw at any point, without giving a reason. Participants will also be reminded that they can miss any questions they feel uncomfortable answering.

5.2 (M*) Explain how you intend to alleviate any psychological or physical

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discomfort and/or distress that may arise? (if applicable)
All participants will be debriefed (please see attached sheet) and given contact details should they wish to ask any questions. Participants will be reassured of the confidentiality of their responses and reminded of their right to withdraw at any point.

5.3 Explain how you will care for any participants in 'special groups' *(i.e. those in a dependent relationship, vulnerable or lacking in mental capacity)* **(if applicable)?**
N/A

5.4 Please give details of any payments or incentives being used to recruit participants (if applicable)?
No payments will be offered to particpants. However, findings from this research will help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life. A brief report of findings will be distributed to participants on completion of the study. Siblings will be provided with a certificate to show that they have participated in the study.

5.5 i) How will participant anonymity and/or data anonymity be maintained (if applicable)? *Two definitions of anonymity exist:* *i)* Unlinked anonymity - *Complete anonymity can only be promised if questionnaires or other requests for information are not targeted to, or received from, individuals using their name or address or any other identifiable characteristics. For example if questionnaires are sent out with no possible identifiers when returned, or if they are picked up by respondents in a public place, then anonymity can be claimed. Research methods using interviews cannot usually claim anonymity – unless using telephone interviews when participants dial in.* *ii)* Linked anonymity - *Using this method, complete anonymity cannot be promised because participants can be identified; their data may be coded so that participants are not identified by researchers, but the information provided to participants should indicate that they could be linked to their data.*
This study will use linked anonymity ie. Whilst data will not be collected anonymously it will be anonymised at the first instance. Once consent forms have been received , participants will be allocated a randomly allocated ID number. A list of names and corresponding ID codes will be stored on a password protected computer, in a password protected file. Questionnaires will then be lablled with the appropriate ID code, before the questionnaire is sent to the participant. Participants, who have selected to complete the questionnaire online, will be sent a link to the questionnaire and a unique code which will allow them to access the questionnaire. Participants unique codes will give them access to a questionnaire already linked to their unique ID number. As for participants completing the questionnaire on paper, a record of unique ID numbers and names will be stored on a password protected file on the computer. Unique ID numbers will be generated once a consent form has been received. By maintaining a list of ID codes and names it will be possible for the reserachers to ensure they do not send multiple questionnaires to the same family, and to monitor the response rate. Linked anonymity will be explained on the participants information sheet (see attachement).

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5.5 ii) How will participant confidentiality be maintained (if applicable)? *Confidentiality is defined as the non-disclosure of research information except to another authorised person. Confidential information can be shared with those who are already party to it, and may also be disclosed where the person providing the information provides explicit consent.*
Confidentiality will be maintained, this will be explained to particiapnts on the information sheet. Data will only be shared once all personal identification has been removed.

5.6 (M*) How will personal data and study results be stored securely during and after the study? *Researchers should be aware of, and compliant with, the Data Protection policy of the University. You must be able to demonstrate this in respect of handling, storage and retention of data.*
Data will be shared only between the researchers and the supervisors. Data will be kept from being accessed by anyone unauthroised. For security data that is kept will be stored securely under undername and passwork protection.

5.7 (M*) Who will have access to these data?
Francesca Leach (Reseracher), Dr. Donna Mccann (Supervisor)

N.B. – Before you upload this document to your ERGO submission remember to:

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