

**HOW DO TYPICALLY DEVELOPING SIBLINGS OF  
AUTISTIC CHILDREN EXPERIENCE THE PARENT  
CHILD RELATIONSHIP?**

**A QUALITATIVE STUDY OF ATTACHMENT AND  
AMBIGUOUS LOSS IN YOUNG CHILDREN LIVING IN  
IRELAND**

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A Thesis Submitted in Fulfilment of the Requirements for the  
Degree of Ph.D

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2023



## **Declaration**

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Paula Harrison

## Summary

Academic accounts indicate that when a family receives a diagnosis of Autism Spectrum Disorder for a child, relationships within the family are affected and undergo change. Research suggests that the unique profile of deficits associated with ASD can be emotionally and psychologically challenging for parents. In addition, having a sibling with this condition changes the family environment for typically developing children in fundamental ways and by default, changes may take place in the parent –child relationship. Qualitative accounts of this, directly from typically developing siblings, are scarce.

This study is concerned with typically developing children, their parents, and the parent child relationship in the context of Autism Spectrum Disorder. These issues are explored qualitatively, primarily from the typically developing child’s perspective. Drawing on qualitative research methods such as interviews, the use of vignette, and the ‘three houses’ interview tool for children, the study aimed to elicit the views, opinions, and experiences of typically developing siblings and their parents to ascertain if and how living with an autistic family member affects their relationship.

Of the 13 participant families, consultation took place with 35 participants – 15 typically developing siblings, 12 mothers, and eight fathers. Throughout the research process, reflexive strategies were employed. The research design, data generation, data analysis, and the presentation of findings were guided by thematic analysis principles and practices such as, purposive sampling, memo writing, and a thematic representation of findings.

The thesis explores how typically developing siblings of autistic children experience the everyday eventualities of being a child, being a sibling and the interaction of these against a backdrop of a home life that, according to academic accounts, can be uniquely exacting. The study is concerned with experiences of typically developing siblings, how they engage with their parents, how they manage their relationship with their parents in times of stress and how they experience life at home considering this. The study also sought the views of parents, with a view to examining their experiences and triangulating their accounts with those from typically developing children.

Thematic analysis saw three overarching themes emerge from the data, namely the ‘forever change’ for the family context wrought by diagnosis, the parent and child’s experience of the ‘push pull’ of parenting amplified, and finally ‘childhood interrupted’ for the child.

The findings describe the experiences of typically developing children at various stages, charting how they found out about their siblings ASD diagnosis, what they understand about this, how this manifests in their relationship with parents, and their experience of everyday life at home. Accounts from children highlight the interdependent nature of the parent child relationship that sees them as agents creating and using strategies to have their needs met. Issues for typically developing children such as changes to the attachment relationship that may result in frustration, experiences of ambiguous loss, and concerted efforts at family resilience, are each discussed. Also highlighted are beliefs that see children viewed by parents as alternately resilient or oblivious to issues as they unfold. Such beliefs can render the child’s emotional experiences invisible to the parent at times.

The importance of the parent child relationship for the typically developing sibling was clear in accounts. A range of experiences communicated illustrated how typically developing children try to negotiate this relationship in a family situation that could sometimes feel overwhelming. Children reported variously, helping out by being a ‘good’ child and caregiver; giving out by fighting or complaining; acting out by getting into trouble at home or school; and getting out by withdrawing from the parent or the home, each used as strategies for negotiating their relationship with parents. Despite evidence that all participant families strive towards resilient family coping, children expressed that the family operated a hierarchy of needs determined by the autistic child’s condition. Accounts suggest that they and parents simultaneously understood and protested this.

All parents described efforts to protect typically developing children from possible negatives inherent in their family situation. However, accounts of the typically developing children who took part suggest that, in spite of some degree of resilience, children did experience stressors related to the parent child relationship in this context, namely, ambiguous loss connected to contextual and relational changes to the parent child relationship; disappointed anticipation characterised by parenting that can be inconsistent and unpredictable; and the loss of their status as children in a home context where parents require them to be more than a child when necessary. In the light of this, this study argues that typically developing children in this context should be seen as persons who may be at

times in need of support and that family intervention should prioritise the parent child relationship as a variable that is amenable to change.

## Acknowledgements

This thesis has been an important part of my life for an extended period of time. I wish to memorialise a huge debt of gratitude owed to several people who supported me throughout.

Firstly I would like to extend sincere thanks to my supervisor Dr. Stephanie Holt. Thank you for your advice and guidance. I will be forever grateful for our many meetings, your kind honesty and your unwavering faith in me with regards to completing this thesis – even when I had thought I might not.

I would also like to acknowledge the support of various individuals in the School of Social Work and Social Policy and the Trinity Research in Childhood Centre in Trinity College Dublin, in particular Professor Mark Morgan who offered insight and words of wisdom related to the developmental psychology dimensions of this project. Several others were there with acts of kindness from time to time such as Dr. Catherine Maunsell, Dr. Helen Buckley, Dr Paula Mayock, Dr. Gloria Kirwan, Dr. Lynn Cahill - your collegiality and generosity are very much appreciated.

To my colleagues at Little Steps Montessori & Naíonra, Christina Whelan and Lynn Carton, thank you for ‘taking the wheel’ in school while I was busy writing. I conducted fieldwork with ease knowing the children in school were in your good hands and I would not have been able to complete this study without your loving support.

In the research field many individuals and support groups demonstrated a great interest in this study. Jump Autism Support, Snowflakes Autism Support Group, Gravity Autism Support Group, Autism Mamaí Ireland, Autism Dadaí Ireland, Let’s Talk Autism Ireland, Irish Autism Mammies and Tallaght Parents Autism Support Group, were each instrumental in facilitating access to participants when this process stalled. I would like to acknowledge their part in helping ensure that this project moved forward to completion.

Beyond academia and work, I had phenomenol support from friends. Dr Catherine O’Dare was unfailingly positive and encouraging. I would particularly like to thank my life long friend Sharon Walsh for listening to my ramblings on our seafront walks - you really kept me going and your encouragement was invaluable.

Most of all, I am forever grateful for the love, support and understanding of my husband Brian and my daughter Ciara. Throughout my years of study you have both been behind me each step of the way, listening patiently while I discussed every idea and supporting me unconditionally at every point in this process. Thank you for the endless cups of tea and the dinners, and for making me take a break even when I did not know I needed one. You are my heart and I could never have done this without you both.

As a young child, my lived experience as a sibling of a sister with an intellectual disability was a positive one. I watched my Mam care for my sister Elaine with endless energy and love and then find even more of that love and energy for her other seven children. Rudyard Kipling once said '*God could not be everywhere and therefore he created mothers*'. To my mother, Mary Lattin who passed away recently, your loss is inexpressible and leaves a wound that will never quite heal. Your love is with me always, your heart is in mine.

Finally, to the families who participated – the 15 children in particular, my heartfelt thank go to you for your contribution. Your courage and generosity in sharing your experiences was humbling. You truly did breathe your hearts onto the pages of this research and I gratefully dedicate it to each and every one of you.



# Table of Contents

Declaration.....	1
Summary.....	2
Acknowledgements.....	5
Table of Contents.....	7
CHAPTER ONE AN INTRODUCTION TO THE STUDY .....	13
Study rationale .....	14
Locating the researcher in the study – on reflexivity.....	19
Research aims and objectives .....	22
What is Autism Spectrum Disorder? .....	23
Clinical Diagnostic Criteria .....	24
Reciprocal Social Interactions and Language.....	26
Repetitive Routines and Behaviours.....	27
A Brief History of Autism – Theories and Debates.....	29
The work of Lorna Wing .....	31
The Neurodiversity Argument.....	32
A Snapshot of Autism Spectrum Disorder in an Irish Context.....	36
Locating the Child in an Irish Context.....	37
Locating the TD Sibling in an Irish Context.....	41
Locating the TD sibling in Ireland going forward.....	44
Conclusion .....	46
CHAPTER TWO LITERATURE REVIEW .....	49
Introduction.....	49
Ambiguous Loss Theory.....	50
Ambiguous Loss and the Family .....	51
Ambiguous Loss and Parenting .....	54
Attachment Theory and the Parent Child Relationship .....	59

Attachment and the TD Sibling .....	61
Parentification and the TD Sibling.....	66
Psychological adjustment and the TD sibling.....	69
Self Concept and the TD Sibling .....	72
Resilience .....	75
Defining Resilience.....	77
Resilience and the TD Sibling .....	78
Family Resilience Theory .....	81
Family Belief Systems .....	82
Family Organisational and Communication Processes.....	83
Family Resilience, Social Support and the TD Sibling .....	84
Conclusion .....	85
The Interface of ASD, Ambiguous Loss, Attachment & Resilience .....	85
CHAPTER THREE THE TD SIBLING, PARENTING AND ASD METHODOLOGICAL ISSUES .....	89
The Research.....	92
The Research Design .....	93
Recruitment.....	95
Phase One – The original recruitment plan.....	95
Phase Two – The supplementary recruitment plan.....	97
Sampling of Families .....	98
The TD sibling participants.....	100
The mother participants .....	101
The father participants .....	101
The Autistic Child.....	102
The Research Setting .....	102
Data Collection .....	105
Parent Interviews.....	106

TD Sibling Interviews.....	108
The ‘Three Houses’ Model.....	108
Vignette.....	110
Ethical Issues .....	111
Informed Consent and Confidentiality .....	112
Ensuring ‘No Harm’ .....	113
Data Analysis.....	115
Validity, reliability and generalizability .....	116
Limitations and Challenges of the Study.....	119
Conclusion .....	121
<b>CHAPTER FOUR DIAGNOSIS AS THE CATALYST FOR ‘A FOREVER CHANGE’</b> .....	122
An Elusive Diagnosis .....	123
Diagnosis - Experiences of Mothers.....	131
Diagnosis – Experiences of Fathers.....	135
Diagnosis – Parent experiences of telling TD siblings.....	139
Diagnosis – Experiences of TD siblings.....	145
Conclusion .....	150
<b>CHAPTER FIVE FAMILY LIFE IN THE CONTEXT OF ASD THE ‘PUSH AND PULL’ OF PARENTING AMPLIFIED .....</b>	152
Introduction.....	152
The Emotional Climate of the Family Home.....	154
Parenting in the Context of ASD .....	159
The interaction of the Emotional Climate and Parenting .....	160
Parental Mental Health .....	165
Differential Parenting .....	168
Parenting and Social Support.....	172
Parenting and a ‘Happy Childhood’ for the TD Sibling.....	177

Conclusion .....	183
CHAPTER SIX FAMILY LIFE IN THE CONTEXT OF ASD CHILDHOOD	
INTERRUPTED .....	185
The Typically Developing Sibling at Home .....	187
The Typically Developing Sibling and the Emotional Climate at Home .....	190
The Typically Developing Sibling and Parenting.....	193
The Typically Developing Sibling and Ambiguous Loss.....	196
The Typically Developing Sibling and Stress.....	199
Typically Developing Sibling, Stress and Defense Mechanisms .....	202
The Typically Developing Sibling and Self Concept .....	208
Conclusion .....	210
CHAPTER SEVEN DISCUSSION AND CONCLUDING COMMENTS .....	218
Introduction.....	218
Reflections on the Research Process.....	218
The Parent-TD Sibling Relationship Revisited.....	222
Ambiguous Loss for the Typically Developing Sibling .....	225
Disappointed Anticipation and the TD Sibling – filling the definitional void.....	228
Family Resilience and the TD Sibling .....	231
Reflections on the Typically Developing Sibling in the Research Process .....	233
Concluding Comments.....	235
BIBLIOGRAPHY .....	242
APPENDICES .....	268
Appendix 1: Letter for Principals.....	268
Appendix 2: Information Sheets .....	270
Appendix 3: Consent Forms .....	280
Appendix 4: Family Demographic Questions.....	286
Appendix 5: Interview Schedules .....	289

Appendix 6: List of Participant Families Profiles, and participant profiles with  
pseudonyms .....302

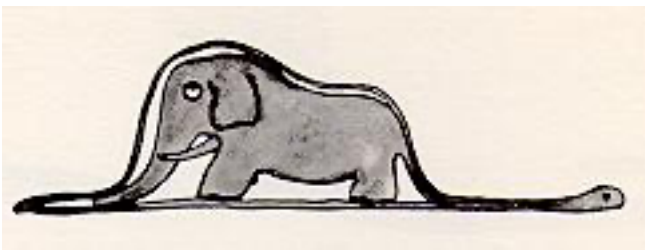
### **An excerpt from ‘The Little Prince’(1942)**

‘After some work with a coloured pencil I succeeded in making my first drawing. My Drawing Number One. It looked something like this:



I showed my masterpiece to the grown-ups, and asked them whether the drawing frightened them. But they answered: ‘Frighten? Why should anyone be frightened by a hat?’

My drawing was not a picture of a hat. It was a picture of a boa constrictor digesting an elephant. But since the grown-ups were not able to understand it, I made another drawing. I drew the inside of a boa constrictor, so that the grown-ups could see it clearly. They always need to have things explained. My Drawing Number Two looked like this:



The grown-ups' response, this time, was to advise me to lay aside my drawings of boa constrictors, whether from the inside or the outside ... I had been disheartened by the failure of my Drawing Number One and my Drawing Number Two. Grown-ups never understand anything by themselves, and it is tiresome for children to be always and forever explaining things to them.’

**- Antoine de Saint-Exupéry (1942), The Little Prince**

# CHAPTER ONE

## AN INTRODUCTION TO THE STUDY

*'I grew up with a little brother whose needs were always more important than mine ... To be the sister of a child with autism means every day is crazy and you never know what to expect ... It's stressful. It's chaotic. You grow up very quickly ... You deal with a lot of emotions and anxieties that never cross the minds of other 8-years-olds ... It is overwhelming at first and that's okay.'*

*Natalie – sibling of an autistic child*

[www.autismspeaks.org](http://www.autismspeaks.org)

As the above quote infers, growing up with a sibling with autism can be a unique experience. The quote is taken from an open letter written by a sister about her younger brother with autism. The letter eloquently gives an insight into the experience of a typically developing (TD) sibling in this context, from the sibling's perspective. There is a paucity of such sibling accounts in the pages of existing research literature concerned with Autism Spectrum Disorder (ASD) and its effects on the family and it has been asserted that middle childhood is largely a neglected area of research (Biehl, Park, Brindis, Pantell, & Irwin 2002; James, Jenks, & Prout, 1998). Moreover, accounts are absent of how TD children in middle childhood living with an autistic sibling experience the parent child relationship. In the broader landscape of research findings, accounts captured directly from children on this issue are also scarce (Hastings, 2014; Petalas, Hastings, Nash, Reilly, & Dowey, 2009). The current study aims to address the silence of TD siblings in autism research by using participant children's words to create a window into their worlds, and so give the TD siblings' experience form and presence within the pages of research. As an organizing motif, this thesis has at its heart a challenge to the idea of the child, to what John Locke called a 'tabula rasa' (Winkler 1996), and it positions the child as a person with agency, an author of her or his own 'story'.

This study is about middle school aged TD children in Ireland and their experiences of their relationship with their parents in the context of their sibling's ASD. The term 'typically developing' (TD) is a term frequently used for research purposes to denote children with no diagnosis, who are understood to be meeting typical developmental milestones. Where other studies report on family experience, particularly mothers' experiences of their autistic child, this qualitative study is primarily focused on presenting the experiences of TD siblings in this context and it is their perspectives which will be foregrounded throughout. Their subjective accounts include their views on how they are parented, how they maintain their connection to the parent, and how they experience their relationship in a context commonly acknowledged by researchers as stressful (Benson & Karlof, 2009; Finnegan, Egan & Trimble, 2014; Phetrasuwan & Shandor Miles, 2009; Smith, Hong, Seltzer, Granberg, Almeida & Bishop 2010). The related accounts of parents are also presented and triangulated with children's accounts in order to answer the research question and provide a contextually rich understanding of TD sibling's narratives.

The introductory chapter aims to outline a context for this thesis by first discussing the rationale for the study, biographically locating the researcher in the study, and then presenting an outline of the research aims and objectives. The chapter goes on to provide a succinct overview of Autism Spectrum Disorder, how it is diagnosed, symptomology, and a brief history of how the condition has come to be understood; in particular, the place of the work of Lorna Wing in this. In addition, the chapter examines the current debates around autism, with a focus on the contribution of the neurodiversity movement to such debates. This is followed by a brief but relevant snapshot of ASD family experiences in an Irish context, followed by an exploration of 'the child' in an Irish context, the TD sibling in a contemporary Irish context, and a related discussion of initiatives and legislation in Ireland that seek to promote and privilege children's perspectives on their own lives.

## **Study rationale**

A diagnosis of autism can be a sensitive and protracted experience for a family, and researchers find that when a child is diagnosed with Autism Spectrum Disorder there are a range of implications for the family unit (Crane, Chester, Goddard, Henry & Hill 2016; Harnett 2007; Howlin & Moore 1997; Hutton & Caron, 2005; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2007; King, Zwaigenbaum, King, Baxter, Rosenbaum &



Bates 2006; Ryan & Salisbury 2012; Siklos & Kerns 2007). Diagnosis affects every member of the family and their relationships with each other. Though experiences are not exclusively negative (Carlsson, Miniscalco, Kadesjö, & Laakso 2016), research finds that in addition to coping with the medical, financial, and educational implications inherent in such a diagnosis, raising a child with the unique profile of support needs associated with ASD can be emotionally and psychologically demanding for parents (Benson & Karlof, 2009; Carbone, Behl, Azor, & Murphy 2010; Genesoni & Tallandini 2009; Lovejoy, Graczyk, O'Hare, & Neuman, 2000; Nissenbaum, Tollefson & Reese 2002; Woodgate, Ateah, & Secco, 2008).

Moreover developmental psychologists argue that, for children, having a disabled sibling may '*alter one primary context of children's lives, their family environment, in fundamental ways*' (McHale, Simeonsson, & Sloan, 1984: 421). Findings suggest that for typically developing children in the family, growing up with an autistic sibling may be stressful on a variety of practical, social, and emotional levels (Gold, 1993; Opperman & Alant, 2003; Vermaes, van Susante, & van Bakel, 2012), as their needs may be eclipsed by the more pressing needs of their disabled sibling. If TD children in this context cope with emotions and anxieties that '*never cross the minds*' of other 8-year olds, as indicated by the sibling letter in the opening of this introduction, it begs the question of how this context might come to bear on the parent child relationship, and how the TD child experiences this.

Extant research literature concerned with exploring the lives of families raising a child with autism focuses largely on the experiences, perspectives, and outcomes for parents (Dabrowska & Pisula, 2010; Finnegan, Trimble & Egan, 2014; Hodge, Hoffman, & Sweeney, 2011; Meirsschaut, Roeyers, & Warreyn, 2010). When typically developing siblings are research participants, research inclines towards examining relationships between the autistic child and siblings (Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003) or aspects of the child's functioning in particular domains (Ross & Cuskelly, 2006; Verté, Roeyers, & Buysse, 2003). Such studies allow only a peripheral view of the TD child's experience related to parents. Indeed, Meltzer & Kramer (2016) argue that the voice of the disabled child is just as absent. Writing in an American context, psychologist and author Barbara Cain (2013) sees TD siblings as autism's '*invisible victims*', often displaced by a sibling whose needs obscure their own. Although the term 'victim' is somewhat melodramatic, the 'invisibility' of the middle school TD child in the pages of the research is clear, in that their experiences run the risk of being a footnote or conflated

with accounts of parents or adolescent TD siblings in research endeavours. Moreover, of 839 studies reported from 2008-2012 in the *Journal of Autism and Developmental Disorders*, only four were devoted to TD siblings. Their primary focus is on genetic risk rather than TD sibling experiences (Cain, 2013).

What *do* we know about sibling experiences from existing ASD research? We know that qualitative TD sibling accounts of their experiences mainly look at quality of life, with a particular focus on the TD child's relationships with their autistic sibling or their peers (Aronson, 2009; Benderix & Sivberg, 2007; Moyson & Roeyers, 2012). This notwithstanding, there are few qualitative TD sibling narratives in the literature relative to those from mothers, for example. Regarding research undertaken with parents, existing findings show that parenting a child diagnosed with ASD is qualitatively different from parenting a child diagnosed with another disability, and therefore the risk of parental mental health problems may be elevated – and this in turn impacts the parenting of all children in the home (Lovejoy et al., 2000; Meirsschaut et al., 2010; Plant & Sanders, 2007; Woodgate et al., 2008).

Related to such findings is the question of the parent-child relationship and how TD children fare in this. Research indicates that when there is a child with a developmental disability in the family, typically developing children notice their parents' elevated stress and may acquire a precocious sense of responsibility towards the parents' psychological, physical and emotional wellbeing (Akhtar, Kennedy, Webster, & Graham, 2012; Barak-Levy, Goldstein, & Weinstock, 2010; Benderix & Sivberg, 2007). Furthermore, young siblings can report ambivalent feelings about their autistic sibling who they may see as frequently monopolising their parents' time and attention (Aronson, 2009; Benderix & Sivberg, 2007; Moyson & Roeyers, 2012; Petalas et al., 2009).

In existing research accounts, TD siblings often reference issues related to parenting such as parental differentiation, perceived neglect, and feelings of being forgotten by busy parents whose energy and resources are often directed towards the child with the disability (Aronson, 2009; McHale, Simeonsson & Sloan, 1984; Moyson & Roeyers, 2012). The TD sibling's 'telling' of the relationship with parents, in projects not designed to examine this topic, suggests that this issue is one that TD children see as important - and they are clamouring to have it heard. Author and poet, Ted Hughes (2009), asserts that 'telling' is about trying to take fuller possession of the reality of one's life. Yet explorations of these issues from the TD child's perspectives are not centralised in research studies and this

particular page remains relatively blank, with the ‘telling’ of experiences shaped by ASD remaining largely with adults.

Research findings have yet to reach a consensus regarding how growing up in this context may shape the TD child’s psychological wellbeing and developmental trajectories. In two meta-analyses, one related to TD siblings of children with chronic conditions such as ASD (Vermaes et al., 2012) and the other with TD siblings of children with intellectual disability (Rossiter & Sharpe, 2001), researchers found a significant small negative effect for having a sibling with additional needs. These negative effects have been attributed to elevated parental stress, social isolation of the TD child, increased caregiving responsibilities within the family for the TD child, and the TD child having to deal with violent and aggressive behaviour from an autistic sibling (Opperman and Alant, 2003; Ross and Cuskelly, 2006). Conversely, there are those studies, and reviews of studies, which find no significant differences between the adjustment of children with typically developing siblings and those who have a sibling diagnosed with ASD (Heller & Arnold 2010; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). These studies argue that negative effects on the TD child are overstated. To support this contention, some researchers highlight positives for TD children such as greater compassion and empathy in siblings of children with an intellectual disability or ASD (Dellve, Cernerud, Hallberg 2000; Petalas, Hastings, Nash & Duff 2015; Kaminsky and Dewey, 2002).

From an ecological perspective, inconsistencies in findings might be understood by considering a myriad of dynamic variables that inevitably come to bear on children’s outcomes. These variables span the micro, mezzo and macro. This fact is acknowledged in the work of several researchers who suggest that variables such as family social economic status, access to healthcare, family size, sibling constellations, marital stress, social support, parental mental health, and family processes may each act as potential risk or protective factors for the TD child (Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari 1996; Kaminsky & Dewey 2002; Kovshoff, Cebula, Tsai, & Hastings, 2017; Macks & Reeve, 2007; Quintero & McIntyre, 2010; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006; Verté et al., 2003). Despite numerous research endeavours, it is argued that the exact mechanisms through which dynamic variables may result in protection or risk for a child remain relatively uncertain (Luthar, Cicchetti, & Becker, 2000; Rutter, 1987). However, seminal resilience research suggests that children considered at risk may thrive despite

adversity, when a triad of protective factors are present in the child's life (Norman Garmezy, 1971; Rutter, 1987; Werner & Smith, 1992). Of these, stable, supportive relationships – usually the parent child relationship – are cited as key in protecting outcomes for children (Bonanno, 2004; Cowen, 1991; Masten, 2001).

The interdependent, transactional nature of the parent child relationship sees children as agents, social actors in their own lives, creating and using strategies to have their needs met (Granic, 2002; Sameroff, 2009). In middle childhood, findings suggest that children refine social emotional skills that they will draw upon throughout life to negotiate relationships and their social world (Eisenberg, Damon, & Lerner, 2006). The emotional climate within the home may be a key factor for developing these skills – and in the situation under study here, the emotional climate of the home unfolds in the context of disability (McHale, Simeonsson, & Sloan, 1984).

The quality of the parent child relationship can be distinguished from other aspects of parenting in influencing the child's developing sense of agency. Research finds that emotional security, which primarily derives from this relationship, is related, not only to the child's sense of *sense* of agency, but to the *exercise* of agency by the child in navigating their relationships and social worlds (Cummings & Schermerhorn, 2003). The parent child relationship is the relational playing field where these skills initially develop and are practiced. It is asserted that a child's ability to exercise agency has implications for their moral development, social interactions, cognitive performance, and efficacy both within and beyond the family unit (Cummings & Schermerhorn, 2003: 93).

Given that the prevalence rate of autism in Ireland is currently 1.5% of the population (Department of Health Report 2018), it is reasonable to argue that increasing numbers of typically developing children in Ireland grow up in a family affected by ASD. However, we know relatively little about how these TD children experience their relationship with parents in this context. Their voices are conspicuously sparse in dialogues around autism between researchers, parents, clinicians, and educators. Children's words, evidence of life as they experience it, are a potential resource then for researchers. Arguably, there is more to the TD child's experience and life stories than the page we are 'stuck' on.

Researchers agree upon the need 'turn the page' and conduct further studies which might make TD siblings more visible in the literature (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011, 2012; Opperman & Alant, 2003). Also acknowledged is the need to

explore parent-child dynamics that are pivotal to the child's development, and which, in the context of ASD may be in need of support (Aronson, 2009; Fisman et al., 1996; Hastings, 2003; Vermaes et al., 2012). Typically, very few studies have addressed issues around the quality of the parent child relationship in this context (Hastings, 2014) by speaking directly with TD children. Therefore, it is reasonable to contend that the experience of the TD child, and their perspectives about the relationship with parents in this context are worthy of investigation. This thesis thus aims to examine what is on the other side of the silence by exploring a fundamental aspect of TD sibling experience by asking, *'How do typically developing siblings of autistic children experience the parent child relationship?'* An exploration of this begins in the next section, which locates the researcher in the research and outlines the study's aims and objectives.

### **Locating the researcher in the study – on reflexivity and bias**

Having returned to third level education as a mature student in 2001, I completed a Bachelor of Arts Degree in Humanities in Dublin City University. Subsequently, I went on to undertake a Post Graduate Diploma in Education at University College Dublin. I worked for several years as a teacher in second level education. Some years later I founded a Montessori & Naionra Preschool and I am now involved in early years educational provision. I undertook this PhD as a teacher working with children of various ages for almost twenty years

In undertaking this project, I was aware of my own position and how that might shape aspects of this work. I am a parent: I am sibling of an intellectually disabled younger sister; I am an Aunt to a disabled nephew; I am a teacher of young children; I am a researcher. These various dimensions to my person had the potential to colour what I looked for, what I saw and how I interpreted that.

Therefore, I engaged in a process of reflexivity throughout the research process, given that I anticipated that I might identify in some respects with the children I was to interview. Finlay & Gough (2003) argue that this reflexivity process is essential to qualitative research, given that the researcher's personal biography and professional experiences are brought to the research process both explicitly and implicitly. Further, McKay, Ryan, and

Sumsion (2003) argue that personal and professional life experience and bias can affect the study design, data analysis, and the presentation of findings.

Kralik (2005) sees reflexivity as engaging in self reflection in order to enhance and balance one's understanding of the researcher and the researched. Therefore, throughout this project, reflexivity for me meant deliberate and intentional reflection in order to consistently balance my 'insider' perspective as an adult sibling myself, with the perspectives of those who were interviewed. I was equally aware of the need to keep any myopic focusing in check when interviewing and to monitor possible 'blind spots' in interpreting and presenting the data. My practice was anchored in Seidel's (1998) model - notice, collect, think; after every interview, I noted reflections in an informal journal. This reflexive practice was pivotal to the integrity of the study.

When I reflect on my personal experience of being a sibling, my memories are overwhelmingly positive. As the third oldest of seven sisters and one brother, I recall our household growing up as a blend of, busy, sometimes chaotic, loud, affectionate warmth. My younger sibling was simply one of the eight children in the household. I do not recall differences in how we were parented or being aware of my parents experiences of my sister. My clearest memory is one of loss when my sister entered residential care at eight years old for a period of two years, and my delight when she came back to live at home.

Despite reflexivity and self reflection, I proceeded with this work in the belief that TD siblings were living through the same experiences as their parents. I expected that despite some stress endemic to family life regardless of how the family is constituted, that parent's and children's experiences would be positive. I entered this work as a sibling and as a parent. I had not fully appreciated how the parent of a child with a diagnosis might experience life in this context. I did not anticipate how this work would change my thinking in this regard and expand my understanding. A more detailed personal reflection on conducting the study is included in the final chapter, a 'reflection on reflexivity' if you will.

The topic of my research was prompted by my current ongoing work in early years educational provision and my relationship with my sister. Issues of difference and disability are integral to my professional and private life. I work daily with a significant

number of autistic children, their families, and subsequently their TD siblings. My work sees me actively engaged with St Michael's House and Centreal Remedial Clinic - planning for child and family needs with multidisciplinary teams and key workers. Having worked with one significantly autistic boy, and having established a relationship with his family, his younger sister attended my preschool two years after her brother had gone on to primary school. Cognisant of some of the details of the family's situation and aware of this little boy's significant needs, it was working with his four year old TD sister that prompted me to wonder what life was like for her at home. Having studied the interdisciplinary subject of Human Development at DCU, I had an established interest in the interaction of sociology and psychology and how these relate to the child's development over a lifespan.

A Dr Seuss decal on the wall of my preschool proclaims, '*A person's a person no matter how small*', and it is one of the principles that underpins my personal philosophy about children. A curriculum requirement in early years education is that young children have 'mark making' materials available to them at all times to facilitate creative representations of their inner worlds and person on paper. My experiences working with children, and my daily encounters with them suggests to me that children can and, indeed, do take pride in 'making their mark'. Children are social actors, natural communicators who create and experience their world as agentic individuals. I regularly observe the ability of very young children to articulate their desires, challenges, and experiences and find this striking. In seeing how articulate the children that I work with are, both verbally and creatively, what strikes me is the untapped wealth of information about children's social reality that can be used to support their development – if only they are asked directly for their views rather than having them represented by parents as proxy respondents. In addition, how would we support TD siblings if their responses were listened to and responded to as the particular social narrative and resource that they are?

I strongly believe that what TD children had to say on this topic is valuable and copious - more akin to a novel than a short story. I feel my experience teaching young children is an asset and I was hopeful that I could design a research project that could counter the silence that conceals TD children in research, comfortably allowing them to participate and be heard. Having participant children's voices as the lynchpin of the study was one of my core objectives so that their narratives, their ordinary words, were the conduit through which all of the 'stories' unfolded. Once written, their accounts could not be unwritten.

Doing this was not without its obstacles. I was aware that conversations with parents around their parenting would be a sensitive issue and equally aware that including children in research - particularly on a sensitive subject - was not going to be easy and may require adaptations as recruitment and field work progressed. This is discussed in more detail in the methodology outlined in Chapter Three, while the research aims and objectives are presented in the next section.

### **Research aims and objectives**

As discussed later in this chapter, historically children have been seen as a low status group. Marginalized as such, accounts of their lived experience often resides on the margins of the pages in research, inhabiting the gaps between the stories of the adults who surround them, or they exist as an addendum to parent or older TD sibling accounts. Given this, this study was couched in two central tenets: firstly, a view of children as active agents in their relationships, and secondly, a firm belief in the ability and the right of the child to be heard as an equal partner in those relationships. The principle aim of the study was to explore children's experiences of the parent child relationship in the context of their sibling's ASD, and place their accounts at the centre of the page.

This was achieved by employing a qualitative methodology exploring this relationship primarily from TD children's perspectives. Implicit in the concept of 'relationship' is the notion of an interdependent connection between two people – each of whom inform and shape the feelings and actions of the other (Bowen & Kerr 1989). Therefore, children's accounts are supplemented by and triangulated with accounts from their mothers and in some cases their fathers also. The objective of documenting parents' experiences also was to provide a more nuanced understanding of this under-researched area and to facilitate a contextually enhanced understanding of the child's experience.

It is against the backdrop of sparse accounts directly from children, described earlier and discussed in more detail in Chapter Two, that the current study set out to explore - from the TD sibling's perspective - the parent child relationships of 6-12 year old typically developing children, living in Ireland, who are growing up with an autistic sibling. Using a qualitative approach, and based on one to one interviews with the children and their parents, the objective was to explore central areas relevant to the parent child relationship. Stated below, the research questions sought to investigate:



1. How do TD siblings experience the parent child relationship in the context of ASD?
2. Do TD siblings perceive their childhood as being sometimes shaped by ASD?
3. How do parents experience the parent-TD child relationship?
4. Do parents perceive that parenting / the parent-TD child relationship as sometimes shaped by ASD?
5. What experiences do TD siblings and parents identify as influencing experiences in and the quality of their relationship?
6. Do parent-reported experiences intersect with issues TD siblings identify as important to them?

It is asserted that family and individual adaptive patterns manifest in family processes, particularly child parent relationships, and these adaptive patterns are key to positive adjustment (Walsh & Firestone, 2012). It might be contended then, that the parent child relationship can act as a key protective mechanism for TD siblings in this context and so is worthy of empirical study. While the precise ways in which interpersonal relationships result in protection or risk for the child are uncertain (Luthar et al., 2000), research on children's attachment relationships and resilience (Atwool, 2006; Rolfe, 2004; Sroufe, 2005a) does support the contention that secure, supportive parental relationships are key in safeguarding developmental outcomes for children (Bonanno, 2004; Cowen, 1991; Masten, 2001). Nonetheless, in the context of ASD, direct consultation with TD siblings about how they experience this relationship is minimal. Therefore, accounts directly from TD siblings are vital if we are to understand their lived experience more fully. The starting point for this is to understand ASD more thoroughly, and by extension the context that TD siblings live within. This is discussed in the following section.

### **What is Autism Spectrum Disorder?**

Descriptions of autism and key diagnostic features used to evaluate ASD have changed over time. Extensive research, together with sociocultural changes, have informed the body of knowledge around autism and the ways in which individuals diagnosed with this condition are perceived and supported. The following section outlines an elementary explanation of ASD, how it is diagnosed, and the profile of support needs associated with the condition, as evidenced in the literature concerned with autism. This is followed by a

brief summary of how the condition has been understood historically, with a particular focus on the work of Lorna Wing, and the current controversies around autism and how it is known with a particular focus on the neurodiversity movement, each of which shape social narratives that contribute to how autism is now understood.

Autism Spectrum Disorder is a complex and lifelong neurodevelopmental condition of uncertain aetiology. According to Silverman (2012: 132), '*Autism has been constituted as a neurological and genetic disorder and this belief is supported by a broad consensus among the research community, but the precise mechanisms of causation remain obscure*'. Revisions of the DSM-5 in 2013 have seen previously separate disorders, namely, autistic disorder (autism), Asperger's disorder, and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS - Childhood Disintegrative Disorder and Rett's Syndrome), reclassified as being one single condition – ASD, with different levels of difference in two core domains discussed later in this chapter. The ways in which ASD is diagnosed is the focus of the next section.

### ***Clinical Diagnostic Criteria***

In 2013, Irish Autism Action commissioned a study by a team of researchers from Dublin City University School of Nursing, entitled '*Autism Counts*'. The study confirmed that the prevalence rate of autism in Ireland is around 1% - similar to UK and US figures (Staines et al., 2013). More recently, estimates of the prevalence of autism in Ireland have been cited as 1.5% of the population (Department of Health Report, 2018).

There are no biological markers that can reliably identify ASD (Silverman, 2015). ASD is diagnosed based on the consideration of a combination of: developmental history, parent interview and reports, behavioural observations and clinical observations. The Autism Diagnostic Observation Schedule (ADOS), designed to assess a child's levels of communication, social interaction and play, together with the Autism Diagnostic Interview-Revised (ADI-R) - a parent/caregiver interview - are used in conjunction with observations and developmental history to reach a diagnosis of ASD (Lord, Risi, Lambrecht, Cook, Leventhal, DiLavore, Rutter, 2000). ASD has been diagnosed in all socioeconomic, racial, and ethnic groups in both children and adults. In addition, the syndrome can present with other medical, developmental, and behavioural support needs (Bartak, 2011; Bauman 2010; Hellings et al., 2005).

Statistically, more males than females are diagnosed with autism, but the reasons for this remain unclear. Early research studies which examine autism report primarily on boys. Reports of girls with the syndrome are increasingly common. The general consensus among researchers is that boys are significantly more likely to be diagnosed than girls (Brugha, 2009; Wing, 1981). The question of whether males are inherently more likely to have autism, or whether autism presents differently in females, thus making it more difficult to diagnose, is one that researchers continue to explore (Attwood et al., 2006; Kopp, Kelly, & Gillberg, 2010). Some researchers contend that girls with Asperger Syndrome are un-referred for diagnosis, and are therefore unaccounted for in ASD statistics (Attwood et al., 2006; Ehlers & Gillberg, 1993; Wing, 1981). It has also been argued that, for girls, the clinical picture may be somewhat different than for boys making diagnosis more problematic (Wing, Gould, & Gillberg, 2011).

Assessments of observable characteristics, in addition to diagnostic tools such as the ADOS and the ADI-R, have historically been informed by the phenotypes delineated by Kanner (1943) and Asperger (1944) in their research with autistic boys. However, it has become apparent to researchers that many girls with autism spectrum conditions have a clinical picture that differs in some ways from boys. Researchers contend that girls have a better ability than boys to mimic others in socially appropriate ways (Kopp, Kelly, & Gillberg, 2010), making diagnosis more difficult in certain cases. Researchers maintain that women with autism are likely to have had a long history of misdiagnoses, with up to 42% having been misdiagnosed with conditions such as schizophrenia, as both disorders have shared clinical features. Given this, researchers argue the need for diagnostic criteria to be revised to reflect the female phenotype (Gould & Ashton-Smith, 2011).

Geneticists have suggested a possible biological basis for differences in statistics between males and females diagnosed with autism. These include genetic and hormonal differences between males and females that may lead to differences in symptoms and in vulnerability to the disorder. For example, one study found autism-linked heritable or spontaneous mutations on the X chromosome (Jiang, Yuen, Jin, Wang, Chen, Wu, & Scherer, 2013). Researchers have speculated that, despite the fact that females may have more mutations, they are less likely to develop diagnosable neurodevelopmental problems. It is theorised that the absence of a second X chromosome in males could make them more susceptible to the effects of such mutations, whereas females, who have two X chromosomes, are protected from such variants (Jiang et al., 2013; Werling & Geschwind, 2013). It is further

hypothesized that females are better at dealing with these severe mutations and males are more at risk for having them result in disease (Jacquemont, Coe, Hersch, Duyzend, Krumm, Bergmann, & Eichler, 2014). Until the aetiology that underlies autism is fully investigated and understood, researchers will continue to speculate.

Despite its heterogeneity, the core domains cited in DSM-V arrange clinical manifestations into two principle areas: reciprocal social communication and interaction support needs plus, restricted and repetitive behaviours and interests. Frith (2003) states that a child must present with all three of the following before age three, to secure a diagnosis of autism. She delineates as follows: there must be qualitative impairment in age appropriate reciprocal social interactions; there must be a qualitative impairment in age appropriate verbal and nonverbal communication; and finally, there must be markedly restricted repertoire of activities and interests appropriate to developmental level (Frith, 2003: 9). An exploration of these symptoms follows in the next section. Although Frith uses the word ‘impairment’, proponents of neurodiversity argue that this is merely ‘difference’ that may be in need of support.

### ***Reciprocal Social Interactions and Language***

In the area of social interaction and language, children with autism can present with varying degrees of symptoms depending upon where they are on the ASD spectrum. Frith (2003) argues that autistic children will often be more interested in playing with objects rather than other children, with things rather than with people. This may be related to issues of language. Children diagnosed with autism often lack skill in the pragmatic use of language, making it difficult for them to communicate effectively (Lord & Paul, 1997; Wilkinson, 1998). In some instances, language may be completely absent, delayed or characterised by echolalia, that is, the repetition of words and phrases. Frith (2003: 123) notes that typically developing children ‘*mainly echo speech that is just above their grammatical competence, and they often modify what they echo, but this may not be the case for autistic children*’. For autistic children, words echoed are often meaningless and without context. Impaired social competence for the ASD child may result from such difficulties, as language is integral to communication, interaction and reading social cues (Lord & Paul, 1997; Wilkinson, 1998). Again, moving away from the language of impairment, if we look at this through the lens of neurodiversity, it might be argued that social behaviours, communication and interaction are as diverse as are individuals.

Research links such language ‘deficits’ to what is termed, a ‘*theory of mind*’ (Malle, 2002) As originally defined, a ‘*theory of mind*’ enables one to understand that mental states can be the cause of, and can be used to predict the behaviour of others (Baron-Cohen, Leslie, & Frith, 1985; Wellman, 1992). Research in developmental psychology suggests that the infant's ability to imitate others lies at the origins of both a theory of mind and other social-cognitive achievements, like perspective-taking and empathy (Meltzoff, 2011). Meltzoff (2011) argues that the infant's innate understanding that others are ‘like me’ allows the infant to recognize the similarity between the physical and mental states apparent in others, and those felt by the self. Theory of Mind is couched in the concept of empathy - the ability to feel for others, the capacity to understand somebody else’s point of view and empathise with their situation - and it is this which is the foundation for all social interaction according to researchers (Baron-Cohen et al., 1985; Wellman, 1992).

Baron-Cohen et al. (1985) assert that a theory of mind is absent in autistic children and controversially it has also been asserted that it is this ability that makes us ‘human’ (Baron Cohen, Gleitman, & Carey, 1997). Recognizing the emotions of others by accurately reading nonverbal cues underpins social communication and interaction. The autistic child’s inability to attribute mental states such as beliefs, desires or intentions to others, or to understand that these mental states may be different to their own, does not detract from their humanness but it does have implications for the autistic child and their families in the areas of imaginative or reciprocal play, and social interactions. Challenges for the autistic child in these areas may result in behaviours that are in need of support and in turn, this can come to bear on relationships for the autistic child and their family, both in and outside the family home. This may then have an effect on how the TD children are parented, as stress for the parent can become elevated.

### ***Repetitive Routines and Behaviours***

A repetitive and restricted repertoire of activities and interests can be characteristic of autistic children. For children with autism, there is comfort in ritual and routine. The restrictions and difficulties that may result for the family and TD children from adhering to these routines are secondary to the security that they provide for the autistic child. In Howlin (2004: 137), Therese Jolliffe, an adult with autism, explains the need for repetition and routine stating:

*Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times and rituals all help to get order into an unbearably chaotic life.*

Repetition and routine may also present in vocalisations and movement. Lewis and Bodfish (1998: 80-82) note that:

*all repetitive behaviours seen in autism are ‘stereotypies ... defined as, repetitive and apparently purposeless body movements (e.g., body rocking), body part movements (e.g., hand flapping, head rolling), or use of the body to generate object movements (e.g., plate spinning, string twirling)...*

They have argued that these repetitive behaviours or ‘stereotypy’ may actually have a pathophysiological basis relating to alterations in dopamine, 5-HT, and opiate systems. From this perspective, these behaviours may be managed with medication, but further research is needed to confirm this. Research also suggests that ritualized and repetitive behaviours are strongly related to anxiety; social anxiety, in particular (Rodgers, Riby, Janes, Connolly & McConachie, 2012). Attwood (1998) asserts that the child’s dependence on routines as ‘soothers’ can increase during times of change, stress, or illness. Therefore, it seems that repetitive movement can function as ‘white noise’ for the autistic child, creating the order they crave, as explained by Therse Jolliffe above.

Much of the literature suggests that limitations on verbal expression coupled with the autistic child’s possible inability to engage in a range of interests in a variety of ways, may constrain children diagnosed with ASD and their families to strictly adhering to pre-set schedules in order to cause minimum distress or sensory overload for the autistic child.

However, when looking at autism with the viewfinder of neurodiversity - which is explored in the next section - it can be argued that the behaviours described above are part of a constellation of behaviours that can be applied to all children to varying degrees at varying stages of their development. Planning and routine is vital for the smooth functioning of all family units, as is developing the ability to recognize relational and contextual antecedents to behaviours considered ‘problematic’ by the family – and difficulty in regulating behaviours can be exhibited by all children, with or without a diagnosis of autism.

Regarding autism, Johnson and Rodriguez (2013) delineate autistic ‘problem’ behaviours as belonging to four broad categories: sensory defensiveness, hyperactivity, non-

compliance, and self-injury. They additionally note management techniques developed by parents over time to manage such behaviours, each of which are informed by current understandings of the condition, which have taken decades to evolve, as discussed in the next section.

### **A Brief History of Autism – Theories and Debates**

In accounts of the history of child psychiatry, there is no mention of childhood autism. While some historical descriptions of psychiatric disorders in children suggest clinical features, which might now be considered akin to Asperger's Syndrome, very few would fulfil the criteria for autism, as it is now understood. Retrospective analysis of some documented cases of 'madness' of adults and children that follow, provide insight into historically and culturally constructed notions about mental health and suggest that a contemporary understanding of autism may well explain cases like those explored by developmental psychologist, Uta Frith, and psychiatrist, Lorna Wing.

For example, contemporary researchers examined the 1747 case of Hugh Blair, a Scottish landowner who was brought before a local court to defend his mental capacity to contract a marriage. Blair's younger brother challenged the marriage to gain Blair's share of inheritance. Houston and Frith (2000) state that recorded legal testimony describes Blair as having some of the classic characteristics of autism; notable deficits in his social relationships, arrested language development, and unusual language patterns, in addition to obsessive repetitive behaviours and uncommon mannerisms. Based on these behaviours, the court found in Blair's brother's favour, annulling the marriage and deeming Blair to be suffering from 'silent madness'.

Similar reports on 'madness' in children have appeared sporadically in publications over time. For example, at the turn of the 19th century, Jean Itard, a French physician, reported on the case of Victor, 'The Wild Boy of Aveyron', an abandoned feral child found roaming in the woods of Aveyron in 1800. Like Blair, the child Victor displayed many features of autism. Itard worked with the child until 1805. The child ultimately learnt to recognize emotions and formed social attachments, and though there was no advancement in his language, he could communicate through writing basic words (Itard, 1962). After

retrospective analysis of these cases, it has been asserted that both Hugh Blair and Victor were undoubtedly autistic (Frith, 2003; Wing, 1997).

It was not until the 1940's that a somewhat contemporary description of autism was articulated, when two psychiatrists in different parts of the world, unknown to each other, first documented a small number of cases. Autism, as a unique syndrome, was not identified until 1943 when Austrian psychiatrist and physician, Leo Kanner, in his paper, *'Autistic Disturbances of Affective Contact'* (1943) used the term to describe the withdrawn behaviour of eleven children he had studied. Kanner did not explore the aetiology of the condition but rather described, in detail, the behaviours of the children he studied in order to communicate the essence of the condition. The children studied by Kanner presented differently as individuals but all shared the same patterns; an inability to relate to people, an absence of speech or an abnormal use of language, and a fixation with repetition and sameness. Kanner labelled the condition infantile autism, seeing it as part of the same family of disorders as schizophreniak; although separate to schizophrenia itself (Kanner, 1943).

Simultaneously, a German paediatrician, Hans Asperger, identified a comparable condition. Written in German, his 1944 paper *'Autistic Psychopathy in Childhood'* provided details of a number of cases where clinical features were analogous to Kanner's (1943) observations of autism, such as problems with social interaction and restricted interests. Asperger's description of autism differed from Kanner's, in that the child's speech was not necessarily delayed, motor deficits were more common, and onset appeared to be later (Asperger, 1944). Essentially, the children studied by Asperger (1944) appeared to be functioning at a higher level than those described by Kanner (1943).

In the early part of the 20<sup>th</sup> century, the work of Sigmund Freud championed the belief that psychological issues in the individual likely emanated from psychological trauma in early childhood. Given that autism was understood as mental illness, it was almost inevitable that efforts to explain and understand the causes of autism veered in the direction of psychoanalytical explanations. In his 1943 paper, Kanner had observed the very cool and reserved demeanour of parents of the children he studied. In his 1949 paper, he suggested that autism was made worse by a dearth of maternal warmth, asserting that the mothers of the children he had observed neglected the emotional needs of their children, attending only to their practical needs which resulted in the children turning away from their mothers to find comfort in solitude (Kanner, 1949). Although he stated that he believed autism to



be innate, he added that the coldness he found in the mothers of these children compounded their problems. His most bald articulation of this belief was in an interview published in *Time Magazine* in July 1960, when he stated that parents of autistic children had just happened to ‘defrost enough to produce a child’ (Thomas, 1960). Bruno Bettelheim, a professor who specialized in child development, at the University of Chicago, endorsed this view. In his book, *The Empty Fortress* (1967), he used psychoanalytical principles and psychological concepts, in addition to case studies of his own, to assert that autism was the result of the failure of mothers to bond with their children (Bettelheim, 1967). His claims were widely accepted by the psychoanalytical community and so the notion of the ‘refrigerator mother’ gained legitimacy.

Concomitant discussions around the possible causes of autism continued and saw speculation that autism was related to schizophrenia and this belief endured until the early 1970’s. In 1971, seminal research highlighted the distinction between the two conditions and influenced the decision to include autism and schizophrenia as two separate categories in DSM-III (Kolvin, 1971). DSM-II had included children with autism under the diagnostic umbrella of childhood schizophrenia. Asperger (1944) had considered issues of aetiology and believed that the autistic psychopathy he observed was biological and probably genetic. Subsequent comparative twin and family studies suggested this to be the case (Bailey, Palferman, Heavey, & Le Couteur, 1998; Folstein & Rutter, 1977). This knowledge went towards discrediting Kanner and, later, Bettelheim’s assertions that autism resulted from parental coldness, the so called ‘refrigerator mother’ theory. The current understanding of ASD as a spectrum condition was largely informed by the work of Lorna Wing, as discussed in the next section.

### ***The work of Lorna Wing***

The full impact of Asperger’s 1944 work remained somewhat muted until 1981 when British psychiatrist Lorna Wing translated Asperger’s original German paper into English (Wing, 1981a). Asperger had used the term ‘autistic psychopathy’ (Wing, 1981a: 115) to describe the ‘abnormal’ behaviour of the children he studied. Wing was disinclined to use the word ‘psychopathy’ because of its negative connotations choosing instead the more neutral term ‘syndrome’. Based on her case studies, Wing (1981a) modified Asperger’s accounts and disagreed with his findings in two significant ways. She argued that contrary to Asperger’s (1944) assertion that, ‘speech develops before walking’ and his references to ‘highly sophisticated linguistic skills’, the children in the cases she studied – when

observed long enough – exhibited language which was, *‘impoverished and much of it is copied inappropriately from people or books. The language used gives the impression of being learned by rote. The meaning of long and obscure words may be known but not those of words used every day’* (1981a: 117).

The second observation challenged by Wing was Asperger’s assertion that people with autism were, *‘capable of originality and creativity in their chosen field’* (Wing, 1981a: 118). Asperger (1944) believed autistic individuals were of *‘high intelligence’* but did not publish findings to support this. Wing (1981a: 118) argued that what Asperger had actually observed were, *‘thought processes...confined to a narrow, pedantic, literal, but logical chain of reasoning’*. Wing’s case studies revealed that the *‘special abilities’* noted by Asperger (1944) might be more accurately described as *‘abilities based on rote memory’* arguing that her case studies demonstrated a notable lack of understanding of the fundamental meaning of what was being said (Wing 1981a: 118).

Wing’s observations contributed to autism being understood as a spectrum disorder ranging, from those severely affected, to those very high functioning in the core domains outlined in DSM V – essentially recognizing a broad variation and diverse differences for the autistic individual regarding IQ, sensory needs, communication skills and repetitive behaviours. Asperger’s description of a high-functioning form of autism, modified by Wing’s work, became formally recognised in the early 1990’s as Asperger’s Syndrome with the publication of the DSM-IV. During the 1980s and 1990s, the role of behavioural therapy and the use of highly controlled learning environments emerged as the primary management approaches for many forms of autism and related conditions.

Currently, the cornerstones of support for autistic children are language therapies and behavioural therapies such as Applied Behaviour Analysis (ABA). The latter, a controversial therapy among autistic communities and neurodiversity advocates (Baker 2011; Silberman, 2015), is discussed in the next section.

### ***The Neurodiversity Argument***

The concept of neurodiversity posits that as humans, our brains vary in terms of how we learn, interact and socialise (Singer, 2017). Through the lens of neurodiversity, these variations are not seen as pathological but rather as merely differences that become disabling by virtue of social barriers that do not allow for such difference (Baker, 2011).

For autistic children, Applied Behaviour Analysis (ABA) is a behavioural therapy, the objective of which is to modify or change observable measurable behaviour through reinforcement. Practitioners assert that when practiced by a skilled tutor, the primary aim of ABA is to work towards various goals - defined by the child's identified interests and needs. This process fosters new behaviours and skills that facilitate learning by rewarding success. Pioneered by Ole Ivar Lovass, ABA has been controversial given that punishing reinforcers were used in its original inception (Baker, 2011). The contemporary use of ABA has dispensed with negative reinforcers that could be construed as punitive and is child led, focusing on nurturing skills that allow the child learn new skills and reduce unwanted behaviours that may hinder learning.

This notwithstanding, attitudes to ABA are decidedly mixed and go to the heart of discussions around the social versus medical model of disability. The medical model automatically sees disability as problematic (Bury 2001). Essentially a person is disabled by their difference or 'impairment'. This is viewed as a 'problem' that lies in and with the individual, a 'problem' that needs a solution. The focus of the medical model is anchored in the idea of what is 'wrong' with the individual rather than what the individual needs to live their life.

Social constructionist Vivian Burr argues that *'the nature of things lies in the relations between them rather than in the things themselves'* (Burr 1995: 107) . This thinking when applied to disability, renders disability a social construct ,where our physical environment can cause, define or otherwise exacerbate a disability. The remedy is to change the interaction between society and the individual through advocacy.

Neurodiversity advocates propose a social model of disability that sees autistic individuals as neurologically different - and autism as something to be accommodated by society through inclusion-focused supports, rather than something to be 'cured'. Proponents of neurodiversity add that autism is problematized by language used by medical and research communities that often position autistic individuals as *'not people in the psychological sense'* (Lovass cited by Chance, 1974: 76), or as persons lacking self awareness and so by implication not fully human (Baron-Cohen, 1999; Frith & Happé, 1999). Author Andrew Solomon (2014) asserts the dangers of attributing such labels, citing attitudes to the possible euthanizing of children with Downs Syndrome in the 1960's as an example of what can happen through history when societies dehumanize people who are different, and

when they collectively insist that all individuals adhere to a particular epoch's notion of 'normal'.

As has happened in other marginalised groups such as the deaf community, the transgender community and dwarf communities, evolving debates in some autistic communities reject constructions of autism as a disability and assert it as an identity (Baker, 2011; Solomon, 2014), a fundamental aspect of personhood – vital to who the individual is as a person; therefore they argue that when exploring issues around autism, 'nothing about us, without us' should be the ruling principle (Baker, 2011; Gillespie-Lynch, Kapp, Brooks, Pickens & Schwartzman, 2017).

In recent years, autobiographies by high profile autistic individuals (Grandin, 2006; Robison, 2009) have contributed to a growing debate that advocates a move away from the 'ableist' model of disability which sees autistic people as broken, and autism as an illness that needs to be cured. Grandin (2006) concedes the usefulness of high quality ABA for very young children, particularly in relation to language development, while Robison (2009) stresses that the focus of ABA should be to teach rather than to suppress or 'normalise' autistic behaviours. Both authors agree that ABA, when implemented well and underpinned by a strength based approach, can support the autistic child in learning to function in areas of interest to the child, and add that this requires input from the child being treated.

That behaviour can be changed through behavioural analysis and conditioning is a fact established by psychological research (Pavlov & Anrep, 1927; Skinner, 1988; Watson, 1970). Research suggests that for autistic children, such changes are best wrought when the ABA tutor is competent, and experienced in applying its principles (Denne, Thomas, Hastings, & Hughes, 2015). However, neurodiversity advocates contend ABA is just another branch of the medicalisation of disability, the insistence that a perceived 'defect' be corrected. Moreover it is argued that the ability to engage in certain behaviours related to autism are often a fundamental need for the autistic person. The behaviours themselves are often harmless and serve an important function for the individual with autism, such as allowing them to self sooth in stressful situations (Rodgers, Riby, Janes, Connolly & McConachie, 2012). This again speaks to the medical model of disability which discounts what the individual needs on favour of fixing what is 'wrong'. Further, advocates ask - should we change an autistic person's behaviour and who benefits from this change? (Silberman, 2015). Moreover, it is argued that ABA has become synonymous with autism

because the majority, that is the non-autistic population, has no tolerance for difference and does not understand the behaviour they observe in the marginalized, that is the autistic population. Activists claim that, motivated by good but misguided intentions, which are underpinned by a medical approach to autism, the majority then embark upon applying ‘remedies’ and ‘cures’ designed to make the autistic individual acceptable to ‘normal’ society – ‘normal’ being defined by the non-autistic population (Silberman, 2015).

Neurodiversity campaigners contend that such ‘normality’ comes at a huge price to the autistic person. A fundamental tenet of ethical practice is to ‘do no harm’, and dissenters question the ethics of ABA which they claim forcefully requires a child behave in ways that may be distressing for the child while simultaneously discounting their immediate needs. Rather than being seen as children who are highly stressed and reacting to that stress, autistic behaviours are often characterized as tantrums or aggression (Smith & Iadorola, 2015) and the purpose of ABA is to extinguish these ‘undesirable’ behaviours. Despite some positives resulting from the use of ABA, findings consistently show variations in outcomes across autistic children (Smith & Iadorola, 2015: 911-912).

Given this, the purported success of ABA in relation to modifying autistic behaviours in the long term has been challenged, and research exists which questions ABA’s usefulness and efficacy, asking if permanent change is realistically achievable (Hassiotis, Poppe, Strydom, Vickerstaff, Hall, Crabtree & Cooper, 2018). It is further argued that ABA traumatises the autistic child depriving them as it might of mechanisms such as repetitive movement that they depend upon to exist comfortably in a world that, for them, feels ‘*unbearably chaotic*’ (Joliffe in Howlin, 2004: 137). The long-term benefits of ABA are also disputed as it has been claimed that the results of ABA may not be changes in behaviour but instead, it can promote symptoms of Post Traumatic Stress (Kupferstein, 2018). This, if true, ironically may increase a child’s dependence on the very behaviours that ABA aims to modify. Although these findings are disputed (Leaf, Ross, Cihon, & Weiss, 2018), more research into this phenomenon might elucidate the long term effects of ABA for the individual.

Whether ABA is successful or not is of little concern to neurodiversity advocates who contend that such therapies are an assault on the identity and personhood of the individual in that; 1) such approaches medicalise autism; 2) discount the needs of the individual; 3) devalue autistic ways of being; 4) attempt to permanently change the authentic autistic self. They add that for children in particular, these changes are often not sought by the

individual child but by the non-autistic adults who surround the child, and it is they who are made most comfortable by the changes to the autistic child's behaviour, forged as a result of ABA. While it continues to be debated, the lens of the social model of disability argues that instead of ABA, the environment is the most malleable determinant of support for autistic children, and it is this that should be the focus of modifications and change rather than the behaviour of the autistic child (Beardon, 2016). Arguably, like all therapeutic approaches to autism, ABA has its history and its limitations and may be most successful when best practice, as outlined by Iovannone, Dunlap, Huber, & Kincaid (2003), is in place and adhered to. For many families, worries about their autistic child go beyond the behavioural as support needs can be diverse and expansive. This is discussed in the next section in relation to families in Ireland.

### **A Snapshot of Autism Spectrum Disorder in an Irish Context**

In 2007, a study by Parent's Education as Autism Therapists (P.E.A.T.), entitled '*Meeting the Needs of Families Living with Children Diagnosed with Autism Spectrum Disorder*', explored questions around meeting the needs of families in Ireland who had a child diagnosed with ASD (Keenan et al., 2007). Participants included 95 parents and caregivers, 88% of who were recruited from ASD charities. Of the 100 children studied, 90 were diagnosed with ASD, 7 with Asperger's Syndrome, 2 with Pervasive Developmental Disorder, and 1 child's diagnosis was undetermined. The study found that the diagnostic process for families took on average 16 months to complete.

Of the families who took part, authors report that 78% had been given a dual diagnoses, meaning that their children were '*diagnosed with ASD as well as intellectual disability, physical and sensory disability, or other concurrent diagnoses*' (Keenan et al., 2007: 59). Despite this, 42% of families were not receiving any form of home support or respite support. In fact, 79% of participants '*disagreed*' or '*completely disagreed*' that they received sufficient support or advice regarding services for their child and family. Family demographics showed that 85% of these families had more than one child. The mean age of the child on the autism spectrum was 8 years old and the mean age of their typically developing siblings was 10 years old (Keenan et al., 2007: 58).

Most relevant to the current study and in relation to TD siblings, the report states that,

*Most of the parents thought that their other children experienced feelings of being neglected (80%) or resentment towards the autistic child (53%), were worried and anxious about their sibling's condition (67%), or felt they were being treated unfairly (67%). On the other hand, many of the parents thought that their other children were very sensitive to the needs of their sibling on the autism spectrum (65%) and/or to the needs of others (58%) and were actively engaged with their sibling on the autism spectrum (73%) (Keenan et al., 2007: 104).*

The perceptions reported by parents in the account cited above suggest that TD siblings are affected by having an autistic sibling, and by extension, their relationship with their parents is affected also. As a result of raising a child with autism, 88% of the parents perceived their own levels of stress as '*highly stressed*' or '*quite stressed*' (Keenan et al., 2007: 110), a fact which Woolfolk and Perry (2011) argue, has implications for parenting.

As previously discussed and as happens with many studies of families with a child diagnosed with ASD, in Keenan et al.'s (2007) study the actual voices of TD siblings are marked by their absence. Typically developing siblings were not consulted or directly asked to report personally about their experiences. By proxy, parents expressed *their* beliefs about their TD child's experience instead. It is this representation of the TD child's experience that often lives on the pages of findings - and it is this lack of the TD sibling's authentic voice that the current study seeks to address. This is discussed in the next section by exploring the place of the child in Irish society historically and the place of TD siblings specifically.

### ***Locating the Child in an Irish Context.***

It has been argued that cultural components attach meaning to the concepts of 'child' and 'childhood', which vary across time and space so that these concepts are historically and culturally specific (James, 2014). Historically, in Western societies, children have been constructed to render them 'seen and not heard', as they have been framed by discourses of incompetence and vulnerability (James et al., 1998). Such narratives are shaped perhaps by far older beliefs that saw children as having no '*mental activity*' (Aries, 1965: 39).

Therefore, conceptualisations of the child's agency and autonomy, or what constitutes 'childhood' have proven fluid, constructed in various epochs to reflect expectations of children linked to a given society's needs and beliefs – and Ireland is no exception. King (2007: 196) succinctly describes the conceptualization of children as depending on '*different societies or ... the same society at different times*', or as James (2014) asserts, history changes our thinking about children and childhood.

The United Nations Convention on the Rights of the Child (UNCRC, 1989) copper-fastened children's rights as active citizens and was ratified by Ireland in 1992. In tandem with this, evolving sociological understandings of children born of the new sociology of childhood, which began emerging over three decades ago (James & Prout, 1997), heralded a shift in how children are understood. This new sociological view of the child framed children as citizens with rights and agency and challenged developmental psychology's theories of childhood. This emerging paradigm argued that children and childhood did not exist divorced from cultural variables and so there were a variety of childhoods rather than one 'natural, 'universal' childhood or child (James, 2014). As discussed below, as a result of such debates children are now increasingly seen as agents, beings in their own lives rather than adults in the making (James & Prout, 1998; Uprichard, 2008). Uprichard (2008: 303) disposes with dichotomy completely and asserts that children are in fact both - *'always and necessarily being and becoming'* and viewing them as such increases a child's sense of agency, as it takes account of who the child is now, in addition to the adult in the making.

In discussing 'battles' surrounding the rights of children in Ireland, Nolan (2007) argued that the Irish Constitution (1937) was family/parent-centric, with children subjugated within the enshrined family unit. Indeed, the Report of the Commission to Inquire into Child Abuse (2009), or the Ryan Report, as it was to become known, suggested that the state sanctioned subjugation of children extended beyond the family, as the Irish Church and State's treatment of children in institutional care over a period of decades was exposed. Cultural shifts in Irish society – fuelled partly by the demise of the Catholic Church (Inglis, 2014), coupled with changes in perceptions of children generated by UNCRC (1989), and the emerging new sociological frameworks for understanding children, saw children repositioned as agentic beings with rights. These developments were key in jettisoning Irish constitutional notions of the 'invisible' child or the child in need of 'special protection' (Nolan, 2007), and placing the rights of 'voiceless' children firmly on political and research agendas (King, 2007).

Author, political activist and human rights advocate Arundhati Roy (2004) wryly argues that, *'We know of course there's really no such thing as the 'voiceless'. There are only the deliberately silenced, or the preferably unheard.'* A new sociological view of children has contributed to an increasing acceptance that children cannot remain silenced or unheard.



Their lived experience, their social reality, and their rights are increasingly being understood as equally as valid as those of adults. In accepting this, by default, a greater recognition has evolved related to the responsibility of adults via government to legislate for and protect the rights of children - and to facilitate a space for children's participation in both political and social decision making (Kellet, 2010). The UNCRC (1989) specified the right to a voice for children, that is, '*the right to express one's views freely – including the right to be heard*' (Montgomery, 2009: 237), and such a voice could only matter if it resounded in the arenas of research and policy development which affects children's lives.

The work of coalitions such as the Children's Rights Alliance (CRA), established in 1995 propelled the issue of children's rights to the forefront of the Irish political agenda and ensured that UNCRC (1989) document did not become a paper tiger in the corridors of government. Members lobbied for reform in legislation and services affecting children across a wide range of issues. This political mobilisation took the form of written submissions to government, oral presentations to Oireachtas All-Party Committees and consultative meetings. Additionally, pioneering work in the development of models for consultation with children, that would allow children's participation in the development of prospective policies affecting them, was also undertaken by the CRA.

The alliance's initial member organisations comprised 65 non-governmental organisations (NGOs) from diverse groupings spanning academia, family support, disability, child protection and other service providers. The CRA worked to secure children's rights by campaigning for the full implementation of the UN convention on the Rights of the Child and the establishment of an Ombudsman for Children. To this end and funded by, among others, the Calouste Gulbenkian Foundation, the Howard Foundation and Barnardos, the CRA commissioned the first-ever Irish study to detail key features of Offices of Ombudspersons for children in various countries, and formulated initial proposals for an Irish office. The resulting report was entitled '*Seen and Heard*', and was published in September 1996. Based on this report, the CRA proposed that Ireland should establish an Office of Ombudsman for Children on a statutory basis, with powers both to promote awareness of children's rights and to investigate individual grievances. The ultimate introduction of the Ombudsman for Children (2002) acknowledged children as citizens with rights (Hayes, 2002), and provided an impartial advocate, a proxy voice for children in the protection of their rights and welfare.

In tandem with this, the CRA's 1997 shadow report to the UN committee, *'Small Voices, Vital Rights'* enabled the UN Committee to examine the Irish State's First National Report under the UN Convention on the Rights of the Child (1989). The resulting UN recommendations became the catalyst for policy and legislative change designed to protect vulnerable children growing up in Ireland by facilitating children's active involvement in matters that affected their lives.

As a result of the work of the Children's Rights Alliance, in 1998 the Irish government gave a commitment to prepare a National Children's Strategy, as recommended by the UN Committee. The resulting strategy, *Our Children – Their Lives: National Children's Strategy 2000 -2010*, constituted a marked attempt by Irish policy makers to adhere to criteria delineated in the United Nations Convention on the Rights of the Child (1989), in particular Article 12 which recognizes the voice of the child. The strategy's objective was to strategically improve the quality of life for children living in Ireland informed by a clearer understanding of children's lives that would result in developing services to meet their specific needs. In efforts to realize this and make participation in services more amenable to children, initiatives of that time undertaken by statutory and non statutory bodies such as the CRA's collaborative document *'Young Voices: guidelines on how to involve children and young people in your work'*, demonstrated intentional efforts to position children as participating citizens in service provision and policy making. Subsequently, to address the lack of child specific rights in the Irish Constitution, the 2012 Children's Referendum on the Thirty-first Amendment to the Constitution (Children) amended the constitution to extend and protect the rights of children living in Ireland in line with international statute.

The current national policy framework for children, *'Better Outcomes Brighter Futures: The National Policy Framework for Children & Young People 2014 – 2020'*, promises that, *'the views of children and young people will be sought and will influence decisions about their own lives and wellbeing, service delivery and policy priorities'* (Department of Children and Youth Affairs, 2014: xiv). The framework also stresses the important role of preventative and early intervention services for children, in order to ensure that each child has access to the necessary support required to allow them reach their potential, both developmentally and educationally. This policy framework specifically aims to advance the status of children, protecting and fulfilling, *'the rights of children ... the diversity of children's experiences, abilities, identities'* (Department of Children and Youth Affairs,

2014: xiv). This will be succeeded by Policy Framework for Children and Young People 2023-2028.

While advocates for children rights such as the CRA welcome changes such as those rendered by the 2012 Children's Referendum on the Thirty-first Amendment to the Constitution (Children), they stress that such changes are not a 'cure all'. The Children's Rights Alliance see this amendment as a starting point, a fundamental springboard requiring supportive measures if the amendment is to live up to its full potential. In exploring the place of children in the research agenda, Charlotte Hardman (1973: 87) compared the position of children to the former position of women, and she refers to children as a muted group, their location in the social sciences marked by their silence. Notwithstanding developments in policy in Ireland in the last two to three decades, it seems that some children living in Ireland are still conspicuously silent in certain areas of research, their voices marked by an absence on the pages of existing findings – despite policy frameworks that seek to remedy this. The implications that this may have for TD siblings of autistic children living in Ireland is discussed in the next section.

### ***Locating the TD Sibling in an Irish Context.***

Prior to the latter half of the last century, a consideration of the position of typically developing children in Ireland living with a disabled sibling was a moot point. Many individuals with disabilities were institutionalised and did not live in the family home, so that a TD child in 1960's Ireland was less likely to experience life at home with their disabled sibling as a TD child in 2019 might (Quin & Redmond, 2003).

The reconfiguration of public health and disability services (The Health Act 1970), and the increase of secular non government agencies concerned with the care and rights of the disabled, generated a move from large institutional type care, to smaller community settings (Quin & Redmond, 2003) from the 1970's onwards. The Needs and Abilities Report (Government of Ireland, 1990) further developed and supported these moves by making several recommendations for the development of disability services and public health services nationally. The gradual decline of religious orders that had been instrumental in healthcare (Inglis, 1987), coupled with the UNCRC (1989) and subsequent national strategies specific to children, caused a shift in attitudes towards children in

general and disabled children in particular which saw care in the home deemed superior and preferable to institutional care.

In 2013, figures from the National Intellectual Disability Database (NIID) show upwards of 27,000 individuals registered as disabled. Care Alliance Ireland (2015: 2-3) document that upwards of 18,000 of those disabled individuals registered with them live in the family home with parents and siblings. Irish Central Statistics Office (CSO, 2012) records show that children regularly provide care for a disabled family member in the home but records are unclear as to whether the care is provided for a disabled sibling or parent or indeed both. The 2011 census documents 187, 112 family members in Ireland caring for a person with a disability but yet again, there are no figures to indicate how many of these family members are siblings of the disabled person (CSO, 2011).

Additionally, the Growing Up in Ireland Study, which specifically includes the age group relevant to this current study, sheds little light on the experience of TD siblings of autistic children. While the study examines if a child has a disabled family member, the child's relationship to this disabled family member, and whether having a disabled family member affects the participant child, again, it does not specify the nature or extent of the disability. One report from the study does however contain a statement very relevant to the issues explored in this thesis. At the launch of a report on children's social and emotional wellbeing, generated by the study, Dr Elizabeth Nixon (2012) stressed that:

*... what goes on within the family has a very important role to play. The quality of parent-child relationships and in particular children's conflict with mothers and fathers represents a significant risk for their psychological wellbeing. Children can also be affected by ... maternal depression, marital dissatisfaction, and economic disadvantage, but children can be buffered from the potentially negative influence of these factors if a positive parent-child relationship can be maintained (Nixon, 2012).*

The disconnect between legislative aims and practice is noteworthy. Without clear and concise data on TD siblings in particular, the life experience of TD siblings of autistic children remains invisible to a large extent. One could argue therefore that without such data, evidence based practice initiatives, and support provision directed at TD siblings of autistic children become problematic. As a result, aspirations such as the one cited earlier from the '*Better Outcomes Brighter Futures: The National Policy Framework for Children & Young People 2014 – 2020*', can ring a little hollow.

Less problematic is how the validity of children's life experience in general is becoming visible in other arenas of Irish life, particularly through the media. Luddy & Smith (2014: 15) argue that narratives of contemporary Irish society have '*the child as its central trope*'. Bolstered by personal representations of childhood in an Irish cultural context, publications and movies such as John McGahern's (2005) '*Memoir*' or Jim Sheridan's (1990) film '*My Left Foot*', based on Brown's 1954 autobiography of the same name, document the position of children in Irish society over time. In '*My Left Foot*' (1990), this change in attitudes is creatively and metaphorically represented in one particular scene where Christy's mother tells him as he attempts to write, '*Go on Christy, go on make your mark*'. In his 2015 book, '*The Children of the Rising*', Joe Duffy extends the 'mark' of Irish children and the recognition of children's experiences and childhood beyond the autobiographical to give, for the first time, a compelling account of the deaths of 40 children during the 1916 Rising in Dublin. By doing so, the author places accounts of these forgotten children firmly within the pages of Irish history.

This social climate, characterized by the validation of children's lived experiences and an appreciation of children with their own social reality, has also by extension contributed to an awareness of the needs of TD siblings of disabled children at a 'grass roots' levels. In relation to ASD, there are some very sanitized representations of autism in media such as those proffered in comedies such as '*The Big Bang Theory*' (2007 – 2019). However, increasingly, media has documented more realistic experiences of TD siblings, while mainstream media in movies such as '*The Black Balloon*' (2008) or '*Please Stand By*' (2017) often portray an unvarnished representation of the kinds of experiences that TD siblings of autistic children can encounter.

In an Irish context, growing awareness of the experience of TD siblings generated by mainstream media has also filtered into family ASD support groups. For example, The National Parents & Siblings Alliance has devised a support booklet for young TD siblings. The Dublin based, Harold's Cross Autism Resources, Therapy and Support, addresses concerns for people with ASD on its website. It also advises parents of the stress that TD children may experience related to their autistic sibling and how to support them. Social media has also facilitated access to information beyond the local community for TD siblings. Various online support groups exist, with many targeting adult siblings of autistic individuals. Of these, SibNet, a support organization for siblings based in the United States, is one of the largest online groups, which offers advice and information for siblings

of people with disability. While the group targets adult TD siblings, one of its stated aims is to increase service provider and parent awareness of younger TD sibling's support needs.

The nature of support provision for TD siblings has also appeared on the research agenda in Ireland where the Sibshop model of support for children, as developed in the 1990's by Don Meyer in the United States, has been the focus. The work of D'arcy, Flynn, McCarthy, O'Connor, & Tierney (2005) with services in Cork explains that the Sibshop model comprises eight, two-three hour sessions where siblings meet peers, socialise and relax together, share the challenges and advantages of having a disabled sibling, and learn how challenging situations can be managed. As a result of this intervention support, D'arcy et al. (2005: 45) report improvements for TD siblings including; better behavioural and emotional functioning, enhanced peer networks, and an increased knowledge about the disability of their disabled sibling.

Despite emerging supports such as this one, a recent qualitative study in the United Kingdom reported that retrospective accounts of childhood from 21 adult TD sibling participants, revealed that the majority of respondents recalled being unacknowledged by professionals dealing with the family because of their sibling's disability (Atkin & Tozer, 2014: 234). Recounting childhood memories, participants reported being ignored or excluded by social workers who spoke only with parents when visiting the family home (Atkin & Tozer, 2014: 234). Participants added their belief that best practice should view TD siblings as 'co-clients' and involve and support them as such (Atkin & Tozer, 2014: 238) in order to ensure a more fulfilling context for family relationships. This significance of this observation is discussed in the next section.

### ***Locating the TD sibling in Ireland going forward***

The importance of ensuring fulfilling family relationships – particularly between siblings - should not be underestimated given current international trends, influenced by advocates of the independent living movement, which has seen calls for a move towards increased supported community living for people with disabilities rather than institutional care. Advocates who lobby for change argue, much as advocates for inclusive education have,

that for disabled individuals the life skills required to exist functionally in a community cannot be fostered in isolation from that community.

In keeping with international trends, documents published by the Health Service Executive (HSE) in Ireland such as *New Directions* (Health Service Executive, 2012), and *Value for Money and Policy Review of Disability Services in Ireland* (Department of Health, 2012) assert the need to provide personalised services and individualised types of service provision for those with disabilities. The implications for TD siblings of this policy agenda is unclear as TD siblings are not referred to, but it is reasonable to contend that TD siblings of autistic individuals will outlive parents in most cases, and so it is TD siblings who will constitute the informal family supports required to maintain a ‘care in the community’ approach to persons with disability (Heller and Arnold, 2010; Heller and Kramer, 2009). Again, the lack of consideration given to, and the lack of consultation with TD siblings in such policy agendas speaks to their invisibility in this arena.

An adult TD sibling’s inclination to engage with and participate in such initiatives may hinge upon the relationship that has evolved with their autistic sibling through childhood. Ormond and Seltzer (2007) argue that previous childhood experiences for the TD sibling will possibly be a mediating factor in sibling dynamics that present in adulthood. Similarly, Dunn (2011) and Johnston and Sandall (2005) contend that often the childhood experiences of the TD sibling have a profound and lasting effect on the quality of their relationship. For TD children, stressful or negative childhood experiences can shape how they feel about their ASD sibling, and unsupported, they may live with unresolved feelings of resentment and anger, frequently related to their perceived neglect by parents because of their ASD sibling’s presence in the home (Atkin and Tozer, 2014). Therefore, harbouring such feelings may impede the implementation of any care in the community initiatives.

Research with young TD children in Ireland living in the context of their sibling’s ASD is necessary. In order to address and pre-empt long term difficulties for TD siblings, research that intentionally documents their first hand experiences with their parents may be the mechanism through which adverse experiences are identified, anticipated and supported to safeguard positive developmental outcomes.

## Conclusion

This introductory chapter has explored the research context by presenting a summarised account of the positioning of typically developing children in existing research and exploring how conceptualisations of the child and beliefs about childhood through time have shaped this. Against a backdrop of conservative cultural Constitutional and legislative forces, the chapter has also examined the complex situation of the child in an Irish context through time, how restrictive and limiting concepts of children are gradually being eroded by social and legislative change, and how this is now beginning to crystallise in the lives of TD siblings of children with autism.

Debates around autism previously discussed demonstrate the social climate often experienced by families raising a child with autism. As well as managing significant logistical and financial burdens in relation to their child's care (Roddy & O'Neill, 2019), sociocultural narratives that construct the autistic child as disabled, and/or socially in need of 'fixing' as discussed here, may have profound effects on how parents view the autistic child and understand their diagnosis. The social construction of 'normality' determines cultural patterns of interaction and communication. When these 'norms' are violated the social interaction is deemed a failure. The result is that autistic patterns of interaction and communication have been stigmatized and labeled as deviant rather than neurodiverse.

This fact may also colour the parents experience within the family unit. If their child is 'failing', this may shake their sense of self as parent. By default, this can affect how they parent their typically developing children also. Although research indicates that increased stress is a fact of life for many families living in Ireland (Keenan et al., 2007: 110), if informed by disabling narratives, the story that a family might tell themselves is that having an autistic child is a tragedy, a story without a happy ending. The medicalising of difference as problematic may compound feelings of uncertainty that families can experience after diagnosis. Conversely, a strengths based framing of the family's onward journey, together with inclusive supports for families that extend to typically developing siblings, potentially equip a families to manage challenges well and parent all of their children optimally (Cappe, Wolff, Bobet, & Adrien, 2011; Hall, Neely-Barnes, Graff, Kreck, & Roberts, 2012; Meadan, Halle & Ebata, 2010; O'Connor & Scott, 2007).

Exactly what supports and interventions for TD siblings should constitute is currently unclear given that little discussion or research has taken place with TD siblings in Ireland



related to the quality of their relationship with their parents in the context of ASD. Data related specifically to this are scant. While this chapter acknowledges progress in terms of research, policy and practice, this study aims to examine in detail the experiences and perspectives of TD siblings, making their voices central so that their stories reside on the page, autonomously and clearly informing findings.

Chapter Two reviews the body of literature related to the theoretical issues and concepts relevant to this study, each of which individually and combined provide a theoretical framework with which to understand parent and TD child experiences and interactions in this context. Married with this theoretical review is a discussion of existing ASD literature, which looks at family functioning, parenting experiences, parental mental health and family social support. Also reviewed is literature on TD children's experiences and TD children's psychological adjustment and functioning in the context of ASD. The review examines how these two bodies of literature speak to each other, how the parent child relationship presents, and how family functioning is shaped in this context.

Chapter Three outlines how the aims and objectives of the study were realised and describes how the research was conducted by delineating the methodological approach underpinning data collection and data analysis. In conjunction with this, is a consideration of the theoretical, methodological, and paradigmatic issues that shaped the research approach. Given that research participants were children, ethical issues are given particular attention and discussed in detail.

Chapter Four is the first of three chapters that presents findings informed by TD sibling and parent narratives. The thematic focus of this chapter is 'Diagnosis and Change'. It looks participant experiences of diagnosis, and the changes to family life that resulted from diagnosis by examining how these changes are processed and understood by all family members - particularly how TD children in the family were told of diagnosis and how they understand this.

Chapter Five reviews accounts of daily family life reported from parents' perspectives. The thematic focus in this chapter is 'The Push and Pull of Parenting Amplified'. This chapter explores the emotional climate in the family home, parenting and parental mental health and social support by looking at how these issues speak to and shape each other in the context of ASD. The findings here also serve to contextualise participant children's accounts.

Chapter Six examines daily life in the home from the TD sibling's viewpoint – that is, the emotional climate in the family home, being parented, coping strategies, and social support, each communicated by the TD children who participated. The thematic focus of this chapter is 'Childhood Interrupted', a theme that encapsulates feelings underpinning accounts of the majority of children and parents who took part in the study.

Chapter Seven summarises and discusses the findings in the context of existing findings - examining the journey of the family from diagnosis to life now. Key issues that emerged from the accounts of participants' experiences are highlighted and discussed. Also considered is how identifying these issues might shape our expectations and understanding of typically developing siblings of autistic children. Additionally is a contemplation of the place and competence of young children in social science research and how findings from their personal accounts might inform best practice and future support provision for families; particularly TD children, in this context.

## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

This study aims to explore the experiences of typically developing (TD) siblings in Ireland, where the family are raising a child with a diagnosis of ASD. Estimates of the prevalence of autism in Ireland are currently 1.5% of the population (Department of Health Report 2018), so this issue is relevant for many families. Central to the present study is an understanding of how TD children, mothers, and fathers experience the parent child relationship in the context of ASD. Key to understanding this are contextual variables in the home such as, stressors for the family related to autism, family functioning, parental mental health, parent experiences, typically developing children's experiences, and finally social support, each of which inform and shape parent-child relationships.

In undertaking this review some limitations in available literature was immediately obvious. The research question explores relationships. Searches of data bases such as Web of Science, PubMed, and Jstor, using research terms such as 'parent child- dyads'/ parent child relationships/ TD child and parent dynamics' 'in the context of ASD', largely produced a plethora of articles concerned with the psychological dimensions of this issue. Cogniscent of the sociocultural literature and literature related to issues of the relatively newer concept of neurodiversity, specific searches were undertaken to explore the research question from these perspectives to little avail. The author acknowledges that the resulting bank of knowledge in this literature review is dominated by the psychological.

The following discussion reviews literature related to the theoretical issues and concepts relevant to this study by outlining the basic tenets of, Ambiguous Loss Theory, Attachment Theory, and Resilience Theory, each of which provides a lens with which to further understand parent and TD child experiences and interactions in this context. Research indicates that ambiguous loss, attachment patterns between parent and child, and family resilience can influence and mould parent and TD child relationships in the context of disability. Concomitant with this theoretical review is a discussion of existing ASD literature, which looks at research findings on family functioning, parenting experiences, and TD children's psychological development and functioning in the context of ASD. The

review examines how these two bodies of literature speak to each other and how the parent child relationship presents in this context.

Resilience researchers contend that despite a variety of studies, the exact mechanisms through which interpersonal relationships result in protection or risk for the child remain uncertain (Luthar, Cicchetti, & Becker, 2000; Rutter, 1987). However, research on ambiguous loss, children's attachment relationships, and resilience (Atwood, 2006; Boss 1999; Rolfe, 2004; Sroufe, 2005) - all of which are discussed in the sections that follow - suggest that constant, supportive relationships are key in how children experience close relationships, a contention supported also by developmental research (Bonanno, 2004; Bowlby 1990; Cowen, 1991; Masten, 2001). This notwithstanding, the quality of the parent child relationship, and how it is experienced by TD children in the context of ASD is under researched, so literature on this topic, specifically, is sparse in the broader annals of extant research findings, as noted in Hastings' (2014) meta review of the literature for the UK charity, SIBS<sup>1</sup>.

### **Ambiguous Loss Theory**

Pauline Boss, the principal theorist of the concept of ambiguous loss, explores family relationships and how families manage stress through family processes such as attachment relationships and family resilience. She defines ambiguous loss as loss that is irresolvable, as it exists without resolution or closure (Boss, 2000). Ambiguous Loss Theory has been used to explore a variety of diverse contexts where loss is experienced as indefinable or irresolvable (Coolhart, Ritenour, & Grodzinski, 2018; Jackson, 2018; Jerves, Rober, Enzlin, & De Haene, 2019; Mcgee, PettyJohn, & Gallus, 2018). Ambiguous loss can be said to occur when a person is physically absent but psychologically present, such as when a loved one goes missing, for example. Alternatively, it can be experienced as a person who is physically present but psychologically absent, such as when a loved one develops dementia or has a diagnosis of ASD. The lack of certainty that characterises ambiguous

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<sup>1</sup> SIBS is a UK charity that exists to support people who grow up with or have grown up with a disabled brother or sister. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings.

loss suspends the grieving process in a chronic way for families, affecting the individual and producing changes in parent-child relationships and the family overall.

### ***Ambiguous Loss and the Family***

The loss of a loved one is usually processed by cultural rituals and markers, which act as what Grainger (2011: 97) in his study of Irish wakes calls, '*bridges*', bridges which '*clear a pathway into the future*'. Grainger (2011) further argues that such rituals are sacred as they allow the bereaved family to make sense of who they are in relation to the person who is now disconnected from them through death. Grief as a result of death is openly expressed and understood as loss, and is usually met with support and sympathy from others. However, unlike death, ambiguous loss lacks definitive information, and the finality that allows grief, acceptance, and change for a family.

Ambiguous loss is also characterised by '*boundary ambiguity*', which has a significant impact on relationships and roles in the family unit that is grieving. In this kind of loss, significant shifts in family relationships and roles see family members '*uncertain in their perceptions*' pertaining to what constitutes a family member, who performs what roles, and who is responsible for which tasks within the family unit (Boss & Greenberg, 1984: 536). In addition, research finds that boundary ambiguity generates stress for each person in the family (Boss, 2000).

O'Brien (2007) asserts that the concept of Ambiguous Loss can be applied to families who have received a diagnosis of autism for a child. Boss and Yeats (2014: 64) use the term '*goodbye without leaving*' to describe the experience of families where a family member has gone missing, and this term equally captures the suspension of grief in a family who have had a diagnosis of ASD for a child. The family are in 'limbo' – bereft of the child they expected and unsure of how to come to terms with this and move forward.

Researchers stress that ASD is a broad-spectrum condition (Attwood, 1998; Cohen & Volkmar, 1997; Frith, 2003; Lord et al., 2000; Silverman, 2013; Wing, 1997) and prognosis for every child is particular to that child, so the family's loss is difficult to quantify, and future outcomes are not easily anticipated.

In applying Boss' (2000) theory to the family who has a child with autism, it can be argued that the child a family expected, and all of the related hopes and dreams, suddenly go 'missing' after they receive a diagnosis. O'Brien (2007: 136) asserts that such a loss for the

family generates stress and the most egregious stressors *'are those changes that are not clear cut but are ambiguous'*. Furthermore, O'Brien (2007) argues that issues of ambiguity are amplified for families with this particular diagnosis because there is great difficulty in accurately predicting developmental outcomes for the autistic child. Moreover, the aetiology of ASD conditions remains unknown, a fact which may compound grief and allow distressed parents blame themselves for the loss related to their child's condition, as Wayment & Brookshire (2018) have found.

Lazarus and Folkman (1984) contend that the ability to cope derives from our capacity to accurately appraise and appropriately respond to a particular situation. A diagnosis of autism is difficult to appraise, as prognosis is equivocal. Researchers note that trajectories for the autistic child cannot be anticipated as predictably as might happen with other disabilities (Gray, 1998, 2002; Silverman, 2013). For the family then, responding to their grief in a functional way is hampered because their situation presents with the many unknowns inherent in ambiguous loss.

Ambiguity for the family is further compounded by the fact that many children with ASD present as 'normal' with no perceptible disability. This exacerbates difficulties for families who encounter a world, which expects a child who looks 'normal' to behave 'normally' (O'Brien, 2007). Researchers exploring the notion of the 'invisibility' linked to ASD find that, because children with ASD exhibit many functional as well as challenging behaviours, the family's loss is not clear to distal others. Researchers have also found that this often results in others being less sympathetic towards the family and thus blind to the loss and stress inherent in their daily lives (Moyson & Roeyers, 2012; Woodgate, Ateah & Secco, 2008).

Frequently, parents of children with a disabling condition attempt to overcompensate for stresses by becoming extraordinary parents (Deatrick, Knafl & Walsh, 1988; Ray, 2002; Rempel & Harrison, 2007; Woodgate et al., 2008). However, ambiguous loss has the potential to generate anxiety, depression and stress related illness for individuals in the family unit (Boss & Yeats, 2014: 66). An examination of the literature that examines family experiences in the context of ASD confirms that TD children and their parents suffer varying degrees of anxiety, embarrassment, stress, and depression, as noted above (Angell, Meaden & Stoner, 2012; Benson & Karlof, 2009a; Dabrowska & Pisula, 2010; Gray, 2002; Hodge et al., 2011; O'Moore, 1978; Plant & Sanders, 2007; Schopler & Mesibov, 2013; Smith, Hong, Seltzer, Greenberg, Almeida & Bishop, 2010; Tehee, Honan,

& Hevey, 2009; Woodgate et al., 2008; Yirmiya & Shaked, 2005). In their exploration of the lived experience of Canadian parents who have an autistic child, Woodgate et al. (2008) found that these feelings were accompanied by an overwhelming sense of isolation that dominates the experiences of parents in this context. The parents in Woodgate et al.'s (2008: 1075) study testified to this, expressing that they lived in '*a world of our own*'.

Participants in Woodgate et al.'s study (2008) reported that having a child diagnosed with ASD affected, not only their parenting, but also every aspect of family life to the point where they reported that a 'normal' life was impossible. Unlike the experience of the death of a loved one, for many families in their study the initial response to the family's loss was social stigmatisation, judgement, and rejection, each underpinned by misconceptions about ASD. Gray (2002: 221) notes that many parents reported that they isolated themselves in an effort to reduce their stress, essentially minimising contact with a world that they felt did not understand their situation. Similar to Gray (2002), families studied by Woodgate et al. (2008) asserted that it was engaging with uninformed people and unsupportive agencies that left them feeling alone in their loss. Woodgate et al. (2008) add that maladaptive attempts to minimise distress that involve isolating the family were often adopted by parents and this in turn isolated the TD siblings in the family. In rejecting a world that they perceive as having rejected them, families may inadvertently deprive TD siblings of edifying supports in their efforts to cope.

The ASD literature indicates that a family's inclination to isolate may be exacerbated in cases of dual diagnosis, that is, when ASD presents with other disorders such as Intellectual Disability, Attention Deficit Hyperactivity Disorder, Epilepsy, Obsessive Compulsive Disorder, Language Disorders, and Anxiety Disorders. Researchers note that this is because in addition to ASD, families must also cope with a myriad of additional syndrome specific behaviours that make their social world difficult to navigate (Gray, 1998; Lunsy, Weiss, O' Grady, & Skinner, 2013; Woodgate et al., 2008)

As a result of dual diagnosis, the family are coping with two conditions rather than one (Lunsy et al., 2013). When this becomes overwhelming, parents may relinquish the care of their autistic child completely (Nakervis, Rosewarne & Vassos, 2011). Parents involved in research report that difficulties stem from the exceptionally demanding behaviours often characteristic of ASD such as; physical aggression directed at others, self-injury, destruction of property, hyperactivity, and verbal aggression (Hellings et al., 2005; Matson, 2009). Parents additionally cite substantial distress for the family - including TD

siblings, caused by, erratic sleep patterns, behavioural problems, issues with feeding and toileting, restraints on family recreational activities/holidays, limits on career aspirations, and worry for the future (Keenan et al., 2007; O'Moore, 1978). As happens with ambiguous loss, many of these issues are experienced 'behind closed doors' so that, as one parent from a focus group study which looked at these issues succinctly sums up: *'friends and family don't understand the devastation and worry that we have'* (Keenan et al., 2007: 107).

That parents are 'behind closed doors' worrying may reflect culturally shaped beliefs about ASD. How a parent thinks, feels and behaves, can be explained by relational dynamics or mechanisms such as the social construction of reality, normative expectations – each of which influences the thoughts and feelings and behaviors of the individual. Neurodiversity advocate and author Andrew Solomon (2014) argues that much like social constructions of lefthandedness or sexual orientation, we will look back in fifty years at ASD and be dismayed at attitudes and narratives underpinned by 'othering' and 'cures'.

Diagnosis, and particularly dual diagnosis, has powerful effects on family members (Lunsky et al., 2013; Woodgate et al., 2008). The complexities of family life may multiply. Confusion often ensues for the family about which issues are causes and which are effects, in addition to what decisions to make around matters of education, medication and respite care. Coupled with this, dealing with multiple agencies may become frustrating if the autistic child's needs remain undetermined and continually under review. Families find themselves dealing with loss and emotions that cannot be resolved as they resurface repeatedly, unnoticed by distal observers. It is ironic then that sometimes parents in this situation can adopt coping strategies that may see them more inclined to isolate in a bid to avoid experiences of conflict and distress with those outside of the family. As a result of this and compounded by ambiguous loss, researchers find that parents may perceive themselves as parenting alone in a highly stressful situation (Barak-Levy, Goldstein & Weinstock, 2010; Woodgate et al., 2008). This is explored in the next section.

### ***Ambiguous Loss and Parenting***

A range of studies exist, some previously discussed, that examine parenting in the context of disability (Abbeduto et al., 2004; Burrell, Ives, & Unwin, 2017; Cashin, 2004; Finnegan, Trimble, & Egan, 2014; Gray, 2002; Griffith, Hastings, Nash, & Hill, 2010; Hodge et al., 2011; Meirsschaut, Roeyers, & Warreyn, 2010b; Nealy, O'Hare, Powers, &



Swick, 2012; O'Moore, 1978; Phelps, Hodgson, McCammon, & Lamson, 2009; Pinquart, 2013; Smith et al., 2010; Woodgate et al., 2008; Yirmiya & Shaked, 2005). O'Brien (2007) contends that ambiguous loss theory provides a framework with which we can understand the differences in parental responses to a child's disability. Boss and Couden (2002) additionally argue that various mechanisms operate when ambiguity is central to a diagnosis. They note that ambiguity engenders a sense of helplessness, which can predispose a parent to feelings of despair and apprehension so that in the context of ASD, ambiguous loss then, '*maintains confusion ... prevents the reorganisation of family roles ... the family's distress remains unverified ... causes even the strongest of individuals to question their view of the world as fair and just ... is psychologically exhausting*' (Boss & Couden, 2002: 1353). It might be argued then that it is the ambiguities, the unknowns of the situation that exacerbate family stress rather than the diagnosis itself or the autistic child. Disability and how we understand it is a reflection of larger cultural belief systems. On the landscape of psychological and neurological theory, the concept of neurodiversity is relatively new so challenges to dominant narratives around ASD can be overshadowed. Culturally, understandings of disability can often be a product of the way we use differences as a way to narrate, organise and interpret our world (Waldschmit 2018)

Related to this, it is acknowledged in findings that the experience of parenting a child diagnosed with ASD is reported differently to parenting a child who is diagnosed with another disability such as Down's Syndrome, or cerebral palsy (Abbeduto et al., 2004; Eisenhower, Baker, & Blacher, 2005; Phetrasuwan & Shandor-Miles, 2009; Woodgate et al., 2008). Bauman (2010) asserts that the key reason for this may be the singular profile of 'deficits' associated with autistic conditions. Furthermore, findings suggest that parents of autistic children have higher levels of stress, depression, fatigue and anxiety when compared to the parents of children with a different disability or parents of typically developing children (Eisenhower et al., 2005; Henderson, Barry, Bader, & Jordan, 2011; Herrmann, 2016); Phetrasuwan & Shandor-Miles, 2009). These increased levels of stress and anxiety may manifest in relationships within the family, such as the parent child relationship with TD siblings.

Ambiguous loss is further defined by Boss (2000) as a relational disorder, caused externally by context rather than individual pathology. The trauma and immobilisation that ambiguous loss engenders has the potential to generate conflict within family relationships (Boss & Yeats, 2014: 66). Boss & Couden (2002: 1353) argue that ambiguous loss '*blocks*

*understanding*' and, by extension, coping. Potentially, this has implications for how the parent relates to and experiences the relationship with the TD child and vice versa.

It is strongly indicated in the literature that parental stress and mental health impact critical aspects of parenting (Dabrowska & Pisula, 2010; Meirsschaut, Roeyers, & Warreyn, 2010; Waters, West & Mendes, 2014). Stress, in particular, does not reside in a vacuum within the individual but is communicated to TD siblings in what Waters, et al. (2014: 934) call '*stress contagion*'. In their study, mother child dyads' autonomic nervous system reactivity was measured simultaneously, and researchers found that children embodied the mother's stress repeatedly - even when the child had not been exposed to a stressor as the mother had. This effect was shown to increase with each exposure to a negative stressor, suggesting that the child is predisposed to attuning to the mother's negative emotional state. Stress often manifests itself through family processes, therefore TD siblings in a family where a parent is stressed as a result of coping with a child diagnosed with autism, may be particularly exposed to its negative effects. Indeed, research which examines self reported stress among TD adolescent siblings of autistic children finds that these siblings are more stressed than TD siblings of children with Down's Syndrome, despite having similar social support (Shivers, McGregor, & Hough, 2019). Moreover, Shivers et al. (2019: 112) report that stress for TD siblings was '*specifically attributed to the brother/sister with autism*'.

Ambiguous loss obstructs coping and is predictive of depression, anxiety, hopelessness, and conflict (Boss, 2000), all of which can corrode and diminish the quality of the parent child relationship. When looking at parenting stress and its effects, existing studies of ASD and the family predominantly look at the experience of mothers and this may be because mothers tend to be the primary carers in this context, and so are exposed to, and must manage autistic behaviours most frequently (Pepperell, Paynter, & Gilmore, 2018; Wayment & Brookshire, 2018; Woodgate et al., 2008). Research findings indicate that mothers of children with autism are more stressed than mothers of typically developing children (Quintero & McIntyre, 2010; Smith et al., 2010) and more stressed than mothers of children with Down's Syndrome (Griffith et al., 2010). Furthermore, when considering TD siblings, the latter finding has its mirror image in the research of Shivers et al. (2019).

Quintero & McIntyre (2010) examined sibling adjustment and maternal wellbeing in families in New York. While findings suggested that TD siblings of children with ASD

were relatively well adjusted, the authors note that the mothers they studied reported significantly higher stress and depressive symptomology. Smith et al. (2010) similarly qualitatively compared the daily lives of mothers of children with autism to mothers of children with no disability. They found that mothers of ASD children reported significantly lower levels of positive affect and significantly higher levels of negative affect in interactions with their children on a daily basis. In addition, they suffered twice as much fatigue and twice as many stressful events, such as arguments, than did the comparison group of mothers. When the concept of stress contagion (Waters et al., 2014) is added to this, it can be argued that the stress experienced by mothers is transmitted to and held by TD siblings in the family also. This may come to bear on parent child interactions, which have the potential to become mired in stress that can affect the well being of both parent and TD child.

Confirming this is a meta analysis of existing data where Verte et al. (2003) examined behavioural problems, social adjustment and self-concept in siblings of children with autism. They found that maternal stress could affect the well-being of TD siblings, even when the autistic child is high functioning. Further, Yirmiya and Shaked (2005), in a meta-analysis of studies between 1973 and 2003, found that both mothers and fathers of children with ASD demonstrated significantly more psychopathology in the areas of depression and anxiety than control parents. Additionally, longitudinal research has found that children of depressed mothers are at significantly increased risk for conduct disorders, anxiety/panic disorders and substance abuse disorders (Weissman, Wickramaratne, Nomura, Warner, Pilowsky, & Verdelli, 2006). Moreover, Evans, Li, & Whipple (2013) found that if depression is chronic and exacerbated by other risk factors such as poverty, marital problems, or inadequate social support, then the detrimental effects on the parent child relationship increases proportionately.

According to Lazarus and Folkman (1984), perception and the resulting response inform coping therefore it might be argued that it is not the severity of the ASD child's condition but rather the parents' appraisal of it that is significant in determining parental mental health and by default, the relationship with TD siblings in the family. The parents' ability to accurately appraise and functionally cope with their situation can be hampered by ambiguous loss, and Gray (2003) found that parents may take refuge in gendered coping responses. In addition, Lovejoy et al. (2000) found that overwhelmed depressed parents can become disengaged from parenting that has become less pleasurable for them.

How parents understand these changes in functioning may also be informed by cultural beliefs and narratives around disability. From a neurodiversity perspective, parenting an autistic child can result in positive life changing experiences for the family, as much as challenges and uncertainty. However, culturally held beliefs can shape and colour perceptions of this. Some powerful examples of the potency of social narratives demonstrate its effects on perceptions of 'ability' and 'disability'. The ancient Chinese practice of 'footbinding' the feet of young girls to keep feet small, often resulted in lifelong mobility issue for the adult women. Culturally, this was not seen as a disability but as a sign of opulence and wealth (Fadiman 2015). Fadiman (2015) further gives the example of how medical thinking can collide with religious cultural beliefs resulting in notions of disability being dismantled, for example in the case of epileptic seizures. In Hmong culture, epilepsy is not seen as illness to be 'treated'. It is understood as a sign the individual is 'chosen' so epileptics go on to the role of a shamen, an important and respected role in their community. Arguably, nothing is but the thinking makes it so and our thinking does not exist in a vacuum but in a social context.

The parent who perceives themselves to be stressed may, metaphorically, absent themselves, detaching emotionally from the TD child. Burrell et al. (2017: 1141) argue that fathers can do this by becoming '*battlefield fathers*', abandoning emotional connections with the TD child in favour of practical solutions for the family. Mothers, in their efforts to be the '*ideal*' sensitive mother (Mesman et al., 2016) to the autistic child, may lose sight of their TD child in the process. Consequently, for the TD sibling, caregiving responsiveness from both parents can become unstable. While very young children may be protected from the consequences of their sibling's diagnosis by their naïve understanding of what is happening (Rubovits & Siegal, 1994), some children may cope by resorting to what Punch (2008) calls backstage behaviours; that is, covert negative behaviours directed at the autistic sibling or parent that discharge feelings of resentment or stress. It can be argued that while the parent is physically present, they may be psychologically absent, and this ambiguous loss for the child may manifest in the attachment relationship to the parent.

The family's experience then can be considered as one that that '*causes a longer and more complicated grief ... chronic grief*' (Boss & Yeats, 2014: 69). In her work with families coping with their child's diagnosis of cystic fibrosis - another chronic health condition - Bluebond-Langer (1996) found that TD siblings are frequently excluded from information that might allow them process their grief, because parents withhold such information in

efforts to protect the TD sibling from issues that they believe are beyond their understanding (Bluebond-Langer, 1996).

How grief is managed is closely related to issues of attachment and resilience for all family members. Boss and Yeats (2014) argue that loss assumes attachment and so attachments relationships must be revised after loss has occurred. Equally, they argue that the resilience levels of the family are central to how the family will cope. Revisions to family roles, family beliefs and family communication – each of which are cited by Walsh (2011) as central principles of family resilience – are required if the family are to ‘live well’ despite ambiguous loss (Boss, 2000). The importance of this for the parent child attachment relationship is discussed in the next section.

### **Attachment Theory and the Parent Child Relationship**

Relationship bonds are central to the issues explored in this thesis. Attachment Theory is a comprehensive psychological theory that provides a framework for understanding how a child creates and maintains close relationship bonds. Attachment is a developmental construct, which centralises the importance of the quality of early caregiver-child relationships that affect a child’s future development. Psychologist John Bowlby’s seminal work in 1958 spotlighted attachment, particularly as a predictor of the child’s social, emotional, and cognitive developmental outcomes going forward.

According to Bowlby (1990), attachment to a primary caregiver – often a parent – evolves for the infant over the early years of development. Behaviours such as crying, smiling, and clinging are biologically driven and designed to elicit proximity to and responses from caregivers (Tronick, Als, Adamson, Wise & Brazelton, 1978). These behaviours are evolutionary and adaptive, in that close proximity to the caregiver ensures the survival of the infant. In addition, they establish intimate emotional bonds with the caregiver. A child will discriminate and direct behaviours towards primary attachment figures, as well as protesting separation from them. The goal of the attachment system for the child is to maintain adequate care and protection which is accompanied by a subjective sense of safety and security. According to Mikulincer & Shaver (2012), it is a system that is activated by stress and remains active over the entire life span.

Bowlby (1990) argues that successful bids for proximity by the child result in security and the ability to down regulate negative emotions, each of which sustains resilience in times of stress. Research suggests that disturbances or deficits in the system may result in psychopathology which has consequences for future psychosocial functioning of the child (Bowlby, 2010; Main, Kaplan & Cassidy 1985; Mikulincer & Shaver, 2012). Furthermore, longitudinal studies link attachment history to a range of developmental outcomes, relating specific patterns of attachment to normal or pathological development for the child (Groh, Fearon, Bakermans-Kranenburg, van IJzendoorn, Steele, & Roisman, 2014).

The early bonds of the attachment relationship inform what Bowlby (1990) calls '*representational models*'. Based on experience, the child internally organizes a cognitive system that informs the child's sense of self and expectations of others. These subconscious internal working models are underpinned by the child's '*real life experience of day-to-day interactions with his parents*' (Bowlby, 1990: 129-130). Essentially, working models of self are, '*built in the mind during childhood are held to be central features of personality functioning throughout life*' (Bowlby, 1990: 123). Research in developmental psychology suggests that children deploy beliefs informed by internal working models in order to negotiate their relationships with self and others, including parents, over their life span (Main et al., 1985; Mikulincer & Shaver, 2012; Bowlby, 1990). Moreover, the role of parents in this process in middle childhood is vital (Oberle, Schonert-Reichl, Guhn, Zumbo, & Hertzman, 2014; Oberle et al., 2014; Rogers, 2004).

Informed by Bowlby's work, a procedure called the Strange Situation Classification was devised by Ainsworth and Wittig (1969) to monitor how a child responded to its mother upon reunion, having been left in the care of a stranger for a short period of time. In a longitudinal study conducted with a group of 26 middle class mothers and their 12-18 month old children in Baltimore, USA, Ainsworth and her colleagues explored the child's use of their mother as a 'secure base' from which to explore the immediate environment (Ainsworth, Blehar, Waters, & Wall, 2015).

Based on observed responses, children's attachment security was categorized as either: secure, insecure-avoidant or insecure-resistant. Ainsworth et al. (2015) assert that the attachment style of the child is the result of early interactions with the caregiver. Secure attachments derive from predictable, sensitively attuned parenting. Insecure attachments result from caregiving that is unpredictable and insensitive to and/or inconsistent with the child's developmental needs (Ainsworth & Bell, 1970). In their study, 'Secure', children

used their mother as a safe base for exploration and were easily comforted by her upon her return. ‘Resistant-Avoidant’ children avoided their mother upon her return or approached her circuitously and were not easily comforted. ‘Ambivalent’ children, despite crying for her, were angry with their mother when she returned and rejected her when she approached to comfort them (Ainsworth & Bell, 1970; Ainsworth, Blehar, Waters, & Wall, 2015).

Most relevant to the current thesis is a third insecure classification of disorganised/disoriented attachment style that was later proposed by Main & Solomon (1986). In the ‘strange situation’, children classified as ‘disorganised’ exhibited a combination of behaviours, including avoidance, resistance, confusion, or apprehension in the presence of a caregiver. Main and Solomon (1986) postulated, just as Ainsworth & Bell (1970) had, that inconsistent responsiveness on the part of parents may be a contributing factor in this style of attachment in the child.

Research literature on ASD and the family demonstrates that challenging autistic behaviours, as outlined by Johnston and Roderiguez (2013), can ensure that parenting in this context is fraught with stress and inconsistency. Such stress and unpredictability can result in parenting responsiveness that is erratic and this has the potential to produce insecure attachments in TD siblings as noted above, particularly disorganized attachment in the TD child. This may have implications for the parent child relationship in this context in that TD children may become insecurely attached to the parent as a result of the context that they live in. The importance of attachment for the TD child is discussed in the next section.

### ***Attachment and the TD Sibling***

Studies which examine social-emotional functioning and adjustment of typically developing children with disabled siblings are broad ranging. In the studies noted here, findings vary, with little consensus on the positive and negative effects for TD children of growing up with a sibling with a chronic condition such as ASD. (Barak-Levy et al., 2010; Davis, 2010; Fisman et al., 1996; Gold 1993; Hastings, 2003; Hodapp, Glidden, & Kaiser, 2005; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Meadan, Stoner, & Angell, 2010; Meyer, Ingersoll, & Hambrick, 2011; Opperman & Alant, 2003; Pilowsky et al., 2004; Quintero & McIntyre, 2010; Roeyers, 1995; Ross & Cuskelly, 2006; Vermaes et al., 2012; Verté et al., 2003) Definitive conclusions about siblings in this context therefore remain elusive. Various issues make studying siblings of individuals with disabilities

problematic: methodological challenges, measurements used, developmental and life course perspectives, mediators and moderators, and cultural issues are all relevant in this regard. Meadan et al. (2010) contend that it may be that these issues account, in some part, for the inconsistencies in research findings.

An examination of the literature, which examines the home and parenting in the context of ASD as previously discussed, suggests that children experience profound contextual and relational changes in the family when a sibling is diagnosed with autism and these may affect the attachment relationship. Research indicates that these changes can begin even prior to the formal disclosure of diagnosis as the parents' relationship with the TD child becomes consigned to the background while the parent is consumed by the long process of securing a diagnosis (Carlsson, Miniscalco, Kadesjö, & Laakso, 2016; Crane, Chester, Goddard, Henry, & Hill, 2016; Ryan & Salisbury, 2012; Siklos & Kerns, 2007). The potential for ambiguous loss for a TD child in this situation is manifold ranging from, the child's loss of aspects of the self, the child's loss of a dependable attachment to a caregiver who can consistently met their emotional and physical needs, and the loss of family life as the TD child has known it. Sibeoni, Chambon, Pommepuy, Rappaport, & Revah-Levy (2019) found that these losses for the TD sibling may be imperceptible and not easily recognised as loss by the adults who surround them, including professionals dealing with the family. Moreover, Sibeoni et al. (2019: 335) argue that global management of the family in this context by professionals should include TD siblings, and view them as '*persons in distress*', rather than excluded, as found by Blubond-Langer (1996).

In other populations where children experience similar kinds of loss, professionals may more readily identify children as '*persons in distress*'. In their study of parents with an opioid use disorder, Mechling, Ahern and Palumbo (2018: 53) explore the effects of drug use on parenting. In applying the concept of ambiguous loss to children in this context, the authors highlight losses for the child including, the psychological absence of the parent, boundary ambiguity, inconsistent discipline, diminished parental sensitivity, and decreased attentiveness to the child's emotional and physical needs. The effects that drug use by a parent can have on parenting and the attachment relationship has much in common with the effects on parent child attachment relationship in the context of ASD in that parenting has the potential to be affected in similar ways. Yet TD siblings in the ASD home are not understood as at risk or monitored by professionals in the way that children of drug using parents might be, as discussed by Hayden (2004) and Woods (1994)



Research indicates that related to the attachment relationship, in a home where a parent is raising an autistic child, risk for the relationship can derive from the fact that once attentively engaged parents may now be regularly preoccupied (Woodgate et al., 2008), agitated (Benson & Karlof, 2009), fatigued (Henderson, Barry, Bader, & Jordan, 2011) and stressed (Phetrasuwan & Shandor-Miles, 2009; Plant & Sanders, 2007) as a result of managing the autistic child. There is then a possibility that diminishing closeness may result in differential parenting that research suggests is characterized by negative interactions, inconsistent discipline or the psychological absence of the parent (Quintero & McIntyre, 2010; Smith et al., 2010). As parents become what Jennings (1987: 430) calls '*perpetual parents*' to the autistic child, family routines are also impacted. Researchers note that activities that were once enjoyable and emotionally rewarding are now governed by the needs of the autistic child (Gray, 1998, Larson, 2006, Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). According to Crespo (2012), as a result of this, little can be planned or counted on, so a 'day by day' approach to family life and parenting is established. This then becomes normality for the TD sibling and the family and the TD sibling will not necessarily understand why this is happening.

In considering how a typically developing child understands their sibling's autism, Glasberg (2000) notes that the TD child's level of cognitive development is central. Piaget describes a concrete operational stage, which unfolds between the ages of 7-11 yrs old, where children develop the capacity to accurately imagine the consequences of an event without it actually needing to happen. They do so by transforming mental representations of things they have experienced in the world, through using imagination. Researchers assert that at this stage children are not capable of more abstract operations involving representations of concepts (Piaget, Tomlinson, & Tomlinson, 2011). Ross & Cuskelly (2006) contend that older TD siblings demonstrate a good understanding of autism and its implications however, Glasberg (2000) and Ferraioli and Harris (2009) argue that younger TD siblings do not.

In order to measure cognitive sophistication in thinking about autism, Glasberg (2000) applied Bibace & Walsh's (1980) cognitive developmental framework to interview a sample of 63 siblings of children with ASD. Children aged 7-10 years old who participated, could describe implications of their siblings condition using concrete operational reasoning but '*could not yet imagine hypothetical situations*' (Glasberg, 2000:

152). The children's understanding of the implications of autism was consistent with expectations for their developmental stage. Their understanding at this stage also suggested that they believed that ASD could be contagious so their understanding was clearly limited. Glasberg (2000) argues that frequent exposure to their autistic siblings behaviours, together with their lived experiences, did not expand TD children's understanding and observed that regarding ASD, parents '*consistently over estimated their child's understanding of its implications*' (Glasberg, 2000: 153). This suggests that changes to the attachment relationship may be noticed but not fully understood by the TD child, with the added issue of the parent not being aware of this.

Findings in Glasberg (2000) suggest a disparity between parental perceptions of the TD sibling and the TD sibling's actual developmental capabilities, which may have repercussions for the parent child relationship. It is possible that the developmental needs of the TD sibling may not be accurately appraised or prioritized by the parent in this context. In addition, expectations of the TD child may be unrealistic, incongruent with their developmental stage and ability. Existing research findings discussed later in this chapter confirm that this is frequently the case for TD siblings growing up with a chronically ill sibling.

Often as a result of loss after a diagnosis of ASD as previously discussed, changes take place within the home that can result in the TD child experiencing conflicted feelings about their autistic sibling and their parents. Children may cope with this by employing defense mechanisms (Cramer, 2015) or may struggle with ambivalent feelings that are difficult to resolve. This is a theme that emerges frequently in literature, which examines life for TD children in this family context. (Aronson, 2009; Bagenholm and Gillberg, 1991; Benderix & Sivberg, 2007; Moyson & Roeyers, 2012; Petalas et al., 2009). Petalas et al. (2009) noticed tension in narratives of research participants, which comprised TD children aged 8-17 years old, who lived with their autistic sibling. In addition to expressing empathy and fear, participant TD children simultaneously expressed a loving acceptance of their autistic sibling that was couched in a desire that the sibling could somehow be different. The behaviour of their autistic sibling frequently resulted in their feeling fearful, angry, embarrassed, and anxious. Similarly, in interviewing 14 TD siblings from five families who had an autistic child, Bendrix and Siveberg (2007: 414-415) found that TD children harboured feelings of sadness for and terror of their autistic sibling because '*autistic behaviour was often frightening*'.

Opperman and Alant (2003) propose that such ambivalence on the part of the TD sibling may be an adaptive attempt to cope with their loss- an endeavour by the child to down regulate responses to stressful events in order to manage negative feelings. Moreover, Main et al. (1985) argue that the ability to down regulate negative emotions is strongly correlated with secure attachment. Therefore, protecting the attachment relationship may be key for the TD sibling in managing these emotions and supporting healthy adjustment- and therein lies the challenge for families in this context.

The typically developing sibling must manage the ambiguous loss that permeates the context they now find themselves in. The TD child must develop an understanding of their sibling's condition and its implications for the family. They must manage experiences that affect their wellbeing yet are out of their control, and they must accommodate changes to the parent child relationship that they may not be able to fully understand. Concurrent with these issues are matters of how the TD child's own developmental needs are perceived and met by parents, how attachment relationships can be maintained and protected, and how the TD child might be supported in adjusting to a changed and challenging family situation where their parents may be less available to them than they previously were.

Research shows that autistic children, in their attempts to have their needs met, often engage in violent or threatening behaviours as previously discussed (Hellings et al., 2005; Johnston & Roderiguez, 2013; Matson, 2009). In attachment theory, Bowlby (1990) talks of a 'secure base' that acts as a refuge for children when they feel threatened or in danger. For the TD sibling of an autistic child, the need for the parent as a 'safe haven' may become problematic if the focus of the 'safe haven' parent is the autistic child who embodies the very threat that the TD sibling seeks protection from. As a result of this, researchers note that the TD sibling can feel, '*unprotected in their own home*' (Benderix & Siveberg, 2007: 414). The TD child's ambivalence and distress may be understood by considering the disruption to a child's attachment relationship with their caregiver, as the parent is now preoccupied with the autistic child, who they may judge more in need of their care and attention.

Hastings (2003) argues a sociological mediator in that viewed from a strength based perspective, children who are older than their autistic sibling have had a period of parenting 'pre-autism' which may facilitate a secure attachment to the parent. This fact is

acknowledged in the work of various researchers who identify contextual variables explored later in this thesis such as; family SES, family size, sibling constellations, and social support, each of which may prove potential risk or protective factors for the TD child in terms of psychological development and adjustment (Fisman et al., 1996; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Opperman & Alant, 2003; Quintero & McIntyre, 2010; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006; Verté et al., 2003).

The family This secure attachment should be protective for the child. However, considering the attachment relationship through the lens of ambiguous loss (Boss, 2000), it can be argued that the TD child has been displaced their autistic sibling. The distress for the TD sibling is inherent in the loss of the parent and the parenting that they once knew. Boss (2000) asserts that loss implies attachment, so arguably the greater the attachment of the TD sibling to the parent pre-autism, the greater the loss experienced by the TD sibling subsequently. The ambiguous loss of the parent in this way is also attended by boundary ambiguity so that roles within the family then '*become equivocal*' (Boss & Greenberg, 1984: 54) and frequently the TD sibling assumes a parental role inconsistent with their age and abilities in their efforts to cope. This 'parentification' of the TD sibling is the subject of the discussion that follows.

### **Parentification and the TD Sibling**

The relationship with the parent is crucially important in middle childhood (Collins, Harris & Sussman, 1995), therefore children will endeavour to maintain it at all costs. Boundary ambiguity in ambiguous loss, as discussed by Boss and Greenberg (1984), is at the core of parentification, which occurs when a child abandons his or her own need for support, comfort, and attention in order to meet the practical and/or emotional needs of the parent or indeed the autistic sibling. Chase (1999) argues that this inversion occurs at the expense of the TD child's development. When reviewing findings, which examine the effects of ASD on the family, it could be contended that the inadvertent parentification of the TD sibling by the parent is a clear and present risk in this context as the attachment relationship can become skewed.

In studies which look at this issue, the TD child's perceived need to be independent and responsible is reported by TD siblings of children with chronic conditions, including

autism (Akhtar et al., 2012; Benderix & Sivberg, 2007). As children grow older, a sense of '*precocious responsibility*' (Benderix & Sivberg, 2007 : 414) becomes more pronounced and this can manifest in anxiety about the autistic sibling and the parents' physical and emotional wellbeing, as found by McHale et al. (1984) and Moyson and Roeyers (2011).

Using a qualitative research design, Moyson and Roeyers (2011) interviewed 17 children aged between 6-14 years old who had a brother with ASD, without an intellectual disability to ascertain their quality of life. They report that the wellbeing of the child with ASD had an effect on the typically developing sibling's wellbeing and TD siblings were '*strongly concerned ... regularly haunted by worries*' extending to their autistic sibling's social relationships, need for protection, and future care (Moyson & Roeyers, 2011: 48). Cross cultural research suggests that depending on the cultural context, the TD sibling's inclination to shoulder excessive responsibility may be compounded by worries about the parent and parental expectations (Tsai, Cebula, Liang, & Fletcher-Watson, 2018).

In extant literature exploring experiences around ASD, parents are often the subjects of TD children's concerns. In studying a sample of eight 7-18 year old children living with a sibling who had a chronic disability due to spinal cord injury, Akhtar et al. (2012) found that TD children often assumed caregiving duties and responsibility for household chores in a bid for approval, or as an attempt to improve their parents' wellbeing in the practical issues of day to day life. Moreover, Akhtar et al. (2012: 307) found that children regularly assumed increased responsibility for their parents' emotional wellbeing stating the '*striking*' fact that TD siblings, '*did not share their thoughts, fears and worries with their parents. Many participants revealed a need to protect their parents from distressing feelings, thus reversing the role of parent and child*'. Additional studies cited below indicate that this is not unusual, while Mudaly and Goddard (2001) argue that parents may even subconsciously recruit children into such behaviours in times of high stress.

As Tsai et al. (2018) did, in studying experiences of TD siblings of autistic children, Benderix and Siveberg (2007: 416) similarly found that TD siblings were, '*afraid of making his or her own needs known for fear of over burdening the parents*'. Hollingsworth, Didelot and Smith (2003) argue that the assumption of the parent role, in a transient manner in times of high stress, may be beneficial to the child. Moreover, Barnett & Parker (1998) contend that while age appropriate caregiving and helping may foster competence in a child, prolonged demands that are incongruent with a child's developmental capacities may be damaging, as the child may be unintentionally 'set up' to fail. Additionally

research finds that parentification of TD children in this context often results in their having less engagement with peers, school and extracurricular interests (Kaminsky & Dewey, 2002; Verté et al., 2003) which can deprive the TD sibling of social support.

Furthermore, it is argued that parentification interferes with the TD siblings' development, specifically their experience of the attachment relationship and their experience of the self as a child with needs (Jurkovic, 1997; Sahoo & Suar, 2010; West and Kelleher, 1991). Moreover, Chase (1999) asserts that this may result in poor relationships and poor differentiation of self from family of origin into adulthood. To compound this, research on attachment by Byng-Hall (2002) suggests that insecure attachment patterns are more likely to contribute to parentification - with insecure-anxiously attached children most likely to engage in compulsive caregiving. Literature discussed earlier that examines parenting in the context of disability suggests that this context is potentially fertile ground for patterns of relating that may see TD siblings engage in behaviours inconsistent with their developmental abilities - possibly the child's attempt to maintain and preserve some semblance of their attachment to the parent. Therefore, a maladaptive 'loop' of interaction can become established where the insecurely attached TD sibling's parentification type behaviours are reinforced by the circumstances the TD child and parent find themselves in.

In this, the risk for the TD sibling resides in their construction of internal working models as outlined by Bowlby (1990). There is a persuasive body of evidence to suggest that internal working models established in childhood, inform self concept and form the base for templates of behaviour that often endure throughout life (Bowlby, 1990). It may not be in the TD child's long-term interest to conceive of the self as only worthy when that self acts as 'helper' or 'caregiver', allowing their own needs to be superseded by the needs of others.

Compounding this further is the issue of parents' evaluation of their TD child's caregiving behaviours. Recruiting a sample of middle class families in South Israel, Barak-Levy, Goldstein, and Weinstock, (2010) compared parents' self-reported experiences with self-reports from 27 TD children who have siblings with autism and 27 children with no disabled sibling. They reported two significant findings; firstly, TD siblings of autistic children had markedly lower levels of participation in extracurricular activities; and secondly, parents and TD siblings defined '*helpfulness/responsibility*' in an almost *dichotomous manner*' (Barak-Levy et al., 2010: 155). Parents considered

helpfulness/responsibility to be positive attributes of the TD child; however, self-reports showed that, for TD children, these same attributes were a source of stress.

Social constructions of children that prize compliance and obedience in the name of the child's own good as discussed by James et al. (1998) may contribute to parents viewing these behaviours as positive without considering the effects on the TD child. Certainly, in some contemporary societies, award ceremonies which bestow accolades on children and adolescents for undertaking caregiving duties in the family, suggest that this practice may be reinforced for the TD child and the parent outside of the family also by culturally shaped notions of what constitutes a 'good' child. Being a 'good' child may not be good for the psychological health of the child in the long term. The psychological adjustment of the TD child related to issues discussed here is explored in the section that follows.

### **Psychological adjustment and the TD sibling**

Related to TD sibling experience is the issue of how experiences can inform a TD sibling's psychological adjustment in the context of disability. The literature concerning the psychological adjustment of TD siblings of autistic children has yet to reach a consensus regarding how growing up in this context may effect a child's outcomes, although Petalas et al. (2009) argue that effective communication between parent and siblings may facilitate adjustment processes. Studying TD siblings has proved a Sisyphean task for researchers, an endeavour that must take account of the complex myriad of influences on a child's outcomes that span microsystems to macrosystems, as discussed by Bronfenbrenner (1986). These are not easily untangled, however. Meadan et al. (2010) argue that cultural, historical, and interpersonal variables cumulatively come to bear on outcomes related to children's development so arguably, focusing on one domain of a child's functioning may only give researchers a snapshot of a much larger and more complex picture. This fact is acknowledged in the work of various researchers who identify contextual variables such as; family SES, family size, sibling constellations, marital stress, social support, parental mental health, differential parenting, and family processes; each of which may prove potential risk or protective factors for the TD child in terms of psychological development and adjustment (Fisman et al., 1996; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Opperman & Alant, 2003; Quintero & McIntyre, 2010; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006; Verté et al., 2003).

In two meta-analyses, one related to siblings of children with chronic health conditions including ASD (Vermaes et al., 2012) and the other, related to siblings of children with intellectual disability (Rossiter & Sharpe, 2001), researchers found a significant small negative effect for having a sibling with additional needs. More specifically, researchers have identified particular risk areas of concern for siblings such as, an increased risk of developing internalising behaviour problems such as depression (Fisman et al., 1996; Ross & Cuskelly, 2006; Rossiter & Sharpe, 2001), externalising behaviour problems such as aggression (Meadan et al., 2010; Ross & Cuskelly, 2006), and negative parent-child interactions and withdrawal from family life (Fisman et al., 1996; Opperman & Alant, 2003; Smith et al., 2010).

For example, Ross and Cuskelly (2006: 77) studied 25 typically developing 8-15 year old siblings of children with ASD and found that 40% of TD siblings had scores on *'the Child Behaviour Checklist that placed them in the borderline or clinical range'*, the normative sample percentage being 6%. Their findings were consistent with Fisman et al. (2000), who sampled 137, 8-16 year old siblings of children diagnosed with pervasive developmental disorder (PDD) – a disorder classified as part of the spectrum of ASD. Compared with controls, they similarly found higher levels of problematic externalising and internalising behaviours among TD siblings of children with PDD. Again, within the framework of attachment theory, Main et al. (1985) argue that maladaptive coping such as this is anchored in insecure attachments which can result in problematic self regulation.

Conversely, there are studies that find TD siblings of children with autism are well adjusted, particularly if they understand why differential parenting happens (McHale and Pawletko, 1992). Several researchers have found no significant differences between the adjustment of children with typically developing siblings and those who have a sibling diagnosed with ASD (Bayat, 2007; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). In fact, Pilowsky et al. (2004: 863) found in their research that TD siblings were *'surprisingly well adjusted'*. Similarly, Macks and Reeve (2007), using quantitative methods, recruited 51 families with an autistic child from special schools in Maryland and Virginia, and compared the TD siblings in these families to a control group of siblings from 36 families with no disabled child, in order to compare the psychosocial and emotional adjustment of siblings. Typically developing siblings were aged between 7-17 years old. Based on self-reports, TD children with an autistic sibling reported having a more positive self-concept, and a positive view of



their behaviour, intelligence and academic performance, than did siblings of non-disabled children. Importantly, the authors here concede contextual variables stating that the presence of child with ASD can enhance psychosocial/emotional functioning of TD siblings when other demographic risk factors are limited. They argue that when multiple risk factors are present: *'It becomes more difficult for the non-disabled sibling to deal with the child with autism, both emotionally and psychologically'* (Macks & Reeve, 2007: 1064).

Related to this, research also finds that protective factors for the child such as family size may also be relevant to the TD sibling's adjustment. Kaminsky and Dewey (2002: 225) found that a larger family size *'appears to facilitate healthy adjustment siblings of children with autism'*. From an attachment theory perspective, in addition to their primary caregiver, children form attachments to significant others. A study by Seibert and Kerns (2009) shows that children will try to meet their own attachment needs when a parent is unavailable by directing secure base attachment behaviours towards siblings, especially if the sibling is older, therefore a surrogate attachment that may be protective is established. However, the attachment needs of said older TD sibling may remain unresolved.

The functioning of attachment redirected towards an available sibling, viewed through the lens of ambiguous loss theory, encapsulates Boss' (2006) notion of *'revising attachments'*. Boss (2010: 144) argues that *'accepting rather than resisting the ambiguity that surrounds a relationship'* allows the individual to engage with aspects of the person that are available and grieve the loss of connections that cannot be remedied. In discussing therapeutic goals for managing ambiguous loss, Boss (2006) further contends that this kind of 'both/and' thinking requires the child to hold conflicting thoughts about the parent, accepting that they are both present and absent, and this manner of thinking is a gateway to sense and meaning making linked to adaptive coping.

Discrepancies between child / parent perceptions and reporting may also be key in understanding why some TD children cope with their loss better than others. Related to previous observations in this review about parent perceptions and parent reporting on the same measures as children, Macks and Reeve (2007) show that parents may see their TD child's social emotional adjustment more negatively than TD siblings themselves report. Similarly, within the research of Barak-Levy et al. (2010), the discrepancy between children's self-report and parent reports is important as it infers the degree to which parents can accurately perceive their TD child's developmental needs and abilities.

Although in Macks and Reeve's (2007: 1065) study, the participant children viewed themselves as functioning better than parents believed, the authors argue that possibly, because parents are largely focused on attending to the needs of the autistic child '*they really do not have an accurate view of the sibling's social and emotional functioning*'. The fact that a parent may not have an accurate view of the TD child's social and emotional and functioning consistent with the child's self concept, may have implications for what they believe about the TD child - and how they parent in the light of those beliefs. The child's self concept in this context is key to the parent child relationship and is discussed in the next section.

### **Self Concept and the TD Sibling**

While Bowlby (1990) and developmental psychologists argue the child's development of self, sociologist George Mead (1967) demarcates his theory from psychological conceptualizations of the self by embedding it in our social experiences and processes. It should also be noted that various sociological and postmodern scholars have argued that there *is* no 'self' (Immergut, 2014). Social psychology and symbolic interactionism (SI) offer theoretical models for the development of self. From an SI perspective, despite the genetics and biology that form consciousness, people are not born with a self. A self is a product of social processes. Unlike social psychology, SI examines differences in development through the lens of social constructionism. To early social psychologists, understanding self development was of interest as an essential component of the process of socialization and the relationship between individuals and society. Social interactionism holds that the self and the social cannot be separated.

Berk (2004), asserts that the ways in which self concept is influenced is debated but argues that the general consensus is that both nature and nurture contribute to how a child understands and experiences the self. Self concept is shaped in early childhood. Moreover, authors of a study which examined the role of the adult in a child's life stress that empathetic adults that surround the child are crucial to emotional health, particularly in middle childhood years (Oberle, Schonert-Reichl, Guhn, Zumbo, & Hertzman, 2014). Interpersonal communication is anchored in self concept, given that we engage with others consistent with our beliefs about who we are, and congruent with our beliefs about who

others perceive us to be. Given this, it is probable that parent child interactions in the context of ASD are informed by the child's perceptions of self.

The perceptions of self and the self concept of TD children with an autistic sibling were examined by Opperman and Alant (2003) who interviewed 19 adolescent siblings of autistic children. As in other studies (Akhtar et al., 2012; Benderix & Sivberg, 2007), Opperman and Alant (2003:448) found that TD siblings in their study were reluctant to share their feelings about their disabled sibling with parents and felt somewhat unsupported – and this occurs particularly if children do not understand why differential parenting is happening (Kowal & Kramer, 1997). On the issue of psychological coping and self concept, researchers found that, in the main TD adolescent coping responses *'are related to how they perceive themselves and their perceptions of how others view them'*. Further, in their comparative cross sectional study, which compared the self-concept of TD siblings of children with autism, with siblings of neuro-typical children, Inam, Kausar, and Abiodullah (2017) found that TD siblings of autistic children had a self concept significantly poorer than the comparative group. Moreover, they add that the presence of a child with autism was a significant predictor of poor self concept.

How we perceive the self and assumptions of how we are perceived by others are strongly linked to internal working models that operate within the individual as outlined by Bowlby (1990). Securely attached children see themselves as competent and see others as safe, in terms of their ability to be vulnerable (Bowlby, 1990). Opperman and Alant (2003) found that only 5% of TD siblings in their study felt well supported by their parents and many reported withdrawing from family life to minimise their distress - essentially a type of self soothing. This may reflect the quality of their attachment relationships because children who are categorised as insecurely attached have difficulty believing that others can be relied upon in times of stress and so TD children may not look to parents for support or alternatively may not be easily comforted by parents if they do as previously discussed.

Related to this, is the work of Ross and Cuskelly (2006), where attempts at self regulating were found to be a consistent coping strategy used by TD siblings. A child's ability to regulate emotions in a healthy way is anchored in the quality of the relationship with the parent. As the Strange Situation model shows (Ainsworth et al., 2015), secure children experiencing distress manage it by turning to an available, comforting parent whose response is built into the child's internal working model and internalised over time. However, insecure children, either minimise or heighten emotional expressiveness, a

strategy which may cause the child problems, as emotions may be expressed in a socially unacceptable manner as argued by Main, Kaplan, and Cassidy (1985). It might therefore be contended that psychological functioning is, in part, contingent upon the quality of the parent child relationship and the healthy self concept that is thought to develop from it - and this relationship may need support in the context of ASD.

On balance, and in relation to TD siblings in particular, Dyson (1999) argues the need for researchers to question assumptions that living with a disabled brother or sister damages the self-concept, behavioural adjustment and social competence of the typically developing siblings. Having undertaken a longitudinal study of 37 school aged siblings involved in early intervention programmes, Dyson asserts that family psychological processes, family relationships (such as the parent child relationship), a family focus on personal growth and social support – each of which are hallmarks of family resilience (Walsh, 2011), may all mediate the psychosocial development of TD children growing up with a disabled sibling. It seems that having a sibling with a disability can be conceptualised as a risk factor, but it is a risk factor that can be mitigated by other factors such as the parent child relationship.

In her critique of attachment theory, educational psychologist Ruth Slater takes issue with presuppositions of attachment theory that transform a specific dyadic relationship to a general, *'characteristic of an individual that extends across relationships'*, arguing that the mechanisms of internal working models do not take account of resilience factors (Slater, 2007: 214). Her argument is somewhat supported by resilience literature given that resilience researcher, Norman Garmezy (1971: 114), found that for some children, in situations where the *'prognosis could be viewed as unfavourable'*, the developmental outcomes for the child are unexpectedly positive. Similarly, Michael Rutter emphasises perception and context as vitally important in relation to resilience and developmental trajectories for children (Rutter, 1981).

In studying psychological resilience in children, researchers endeavour to understand why it is that some individuals flounder when faced with adversity while others, faced with similar difficulties and stresses, tolerate them well or even thrive. Certainly, research on TD sibling adjustment previously discussed here confirms that outcomes for children in the context of ASD can vary with some TD children developing maladaptive coping mechanisms while others do not.

In the study of resilience, which is the subject of the next section, research has moved away from psychopathology to explore and identify attributes and processes that facilitate positive adaptation, despite the presence of ‘risk’ in a child’s life. Researchers see resilience as a developmental process, and certainly resilience as a construct has much in common with goals for treatment outlined by Ambiguous Loss theorists (Boss, 2006) which include, finding meaning, normalising ambivalence, and discovering hope. Boss (2006) also includes revising attachment as a goal for treatment therefore Attachment Theory, Ambiguous Loss Theory and Resilience Theory are complimentary theories (Masten, 2001). Each has the potential to highlight additional dimensions to the parent child dynamic in the context of ASD. In the next section, resilience in relation to the TD sibling is discussed.

## **Resilience**

The following section provides a brief overview of three influential seminal works, which inform current concepts of resilience, as they were pivotal in generating empirical studies designed to explore positive adaptation in contexts of adversity. This is followed by a discussion of debates surrounding the concept of resilience and its definition. Finally, situated in this framework there is an exploration of risk and protective factors as they pertain to the development of resilience in TD children living in the context of ASD.

Generated by his research into adult schizophrenia and competence, psychologist Norman Garmezy (1971: 114) conducted work which reviewed vulnerability research on children who were considered high-risk groups. Among these children, he found a sub-group who, despite their risk, evinced: ‘*the hallmarks of competence*’ – these ‘*invulnerables*’, who Garmezy (1971: 114) considered a neglected group in terms of research, were ‘*healthy children in unhealthy environments ... seemingly immunized*’ against disorder and maladaptive behaviours. Moreover, he asserted that it might be more beneficial for policy makers if researchers were to study ‘*the forces that move such children to survival and to adaptation*’, in a move away from psychology’s prevailing focus on pathology (Garmezy, 1971: 114).

Similarly, Michael Rutter’s (1964-1974) studies of children in the Isle of Wight sought to discern the aetiology and prognosis of psychopathology in 9-11 year olds by studying a group of ‘at risk’ children. Subsequent to this, Rutter, Tizard, Yule, and Whitmore (1976) noted that a number of children studied did not manifest predicated maladaptive

behaviours despite their 'at risk' status. Risk contexts such as marital discord, parental mental health disorders and low socioeconomic status were identified as significant by researchers. Ultimately, researchers identified a triad of protective factors for children, namely, a positive personality in the child, a supportive family environment and a developmentally supportive community agency such as school, noting that these protective factors could buffer children against the ill effects of risk that may be present in their lives (Rutter, Tizard, Yule & Whitmore, 1976).

A final landmark study in the area of childhood resilience was conducted by Werner and Smith (1982), on the Hawaiian island of Kauai. Beginning in 1955, this longitudinal study examined a multiracial cohort of 698 individuals from infancy to adulthood, exploring the impact of a variety of risk factors, stressful life events and protective factors in their lives (Werner & Smith, 1982). Risk contexts studied mirrored Rutter et al. (1976). Despite the presence of one, and in some cases many risk factors, Werner and Smith (1982) found that one in three of the children studied grew to be well adjusted adults, competent in various domains, and on par with peers who had grown up in optimal circumstances.

As Rutter et al. (1976) had, Werner and Smith (1982) concluded that protective factors for children were both internal and external to the child, and included the disposition of the child, warm family ties, and supports to the child external to the home. They further contended that these protective factors had a safeguarding effect, which protected children in the context of risk. These studies suggested that exposure to risk did not inevitably result in poor developmental outcomes for children. The studies also gave rise to significant concepts, definitions and terminology used to frame subsequent research undertaken in the area of childhood resilience, terms which in themselves are acknowledged by researchers to be somewhat equivocal and problematic in terms of definition (Kaplan, 1999; Kirby & Fraser, 1997; Luthar, Cicchetti, & Becker, 2000).

In the research community, debates on various issues such as: how resilience is defined; resilience as an individual trait or a dynamic process; what constitutes adversity/risk; what can be considered positive adaptation, and the multidimensional nature of resilience across varying levels of risk and protection, are replete in the literature and are addressed in the following section.

## ***Defining Resilience***

In their critical evaluation of the construct, Luther et al. (2000) concede that a central difficulty facing resilience researchers is the diverse ways in which resilience is defined and conceptualized. The term resilience itself has evolved from initial descriptions that give precedence to resilience as a personal attribute, to later explanations that take account of social context and processes. Resilience has variously been described as:

*Invulnerable children ... children who despite ...disadvantage, continue to adapt and perform competently (Garmezy, 1974: 65).*

*Protective factors which modify, ameliorate or alter a person's response to some environmental hazard that predisposes to a maladaptive outcome (Rutter, 1987: 316).*

*A dynamic process encompassing positive adaptation within the context of significant adversity (Luthar et al., 2000: 543).*

*A class of phenomena characterised by good outcomes in spite of serious threats to adaption or development (Masten, 2001: 228).*

*In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural and physical resources that sustain their wellbeing, and their capacity individually and collectively to negotiate for these resources to be provided in culturally meaningful ways (Ungar, 2011: 10)*

The evolution of definitions illustrates unabating discussion among researchers regarding conceptualisations of resilience. In early studies, resilience was conceptualised as intrapersonal (Murphy & Moriarty, 1976; Werner & Smith, 1982), an innate coping capacity or personality trait in a child that privileged personal agency above all else, essentially a '*super-child*' (Anthony & Cohler, 1987: 40). More recently, it has been argued that an individualistic 'trait' approach to the study of resilience is limiting, as it does not take account of nuances that affect outcomes for children in adverse circumstances (Ungar, 2013). Furthermore, Ungar (2013: 14) maintains that, when considering resilience, the personal attributes of the individual are far less reliable in predicting developmental trajectories than the '*cluster of ecological factors*' that can determine well adjusted human development. The primary ecological context for children is the family.

Addressing debates about how resilience should be defined, Luthar et al. (2000: 544) contend that while literature on resilience, *'reflects little consensus about definitions'*, there is a wealth of *'synchronous evidence'* in findings regarding many correlates of resilience. Luthar and Cicchetti (2000) contend that, overwhelmingly, definitions are anchored in two principal concepts: adversity and positive adaptation. Definitions of these concepts are manifold and continually debated (Masten, 2001; Rutter, 1981, 2006). Closely related are the concepts of risk and protection. For the purposes of this thesis, the ways in which risk and protection relate to the TD sibling and this is the focus of the next section.

### ***Resilience and the TD Sibling***

The general consensus among resilience researchers is that adversity or risk is the central antecedent of resilience (Bonanno, 2004; Ungar, 2013). Risk factors are personal characteristics or environmental conditions scientifically proven to increase the likelihood of problem behaviour, or according to Luthar and Cicchetti (2000: 858), *'negative life circumstances that are known to be statistically associated with adjustment difficulties'*. In addition, the concept of risk has been argued by researchers as the 'snowballing' of various stressors, less important in isolation but statistically significant cumulatively (Appleyard, Egeland, Dulmen, & Sroufe, 2005; Masten, 2001; Sameroff, Gutman & Peck, 2003). This is particularly relevant for a TD sibling in the context of the ASD home.

The existing literature on ASD and the family suggests that for TD siblings of autistic children, 'risk' resides in the context in which the child lives and these risks mirror risk contexts studied by resilience researchers discussed earlier. Research findings suggest that TD children in this context may be raised by parents with mental health issues (Baker, Blacher, Crnic, & Edelbrock, 2002; Dabrowska & Pisula, 2010; Hodge et al., 2011; Phetrasuwan & Shandor Miles, 2009; Smith et al., 2010), as well as reduced financial resources (Cidav, Marcus, & Mandell, 2012; Gallagher & Hannigan, 2014). The children themselves may negatively experience differential parenting (Boyle et al., 2004; Chan & Goh, 2014; Tsao, Davenport, & Schmiede, 2012), and parentification (Barnett & Parker, 1998; Byng-Hall, 2002; Saha, 2016). Each of these represents a risk for the parent TD child's relationship. Yet despite these risks there are studies to suggest that children many emerge from childhood in this context relatively well adjusted (Bayat, 2007; Kaminsky & Dewey, 2002; Macks & Reeve 2007; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004).



On this very point, it has been argued that issues of statistical risk versus actual risk must also be considered when exploring these issues (Luthar et al., 2000). For example, citing research on children of drug addicted mothers (Luthar, Cushing, Merikangas, & Rounsaville, 1998), Luthar (2000) argues that children deemed by researchers to be statistically ‘at risk’ because of the stress inherent in being parented by an addicted mother, may in reality actually face low proximal risk if extended family supports are in place. Related to this point is the role of the individual’s cognitive appraisal of stress. Risk can only be significant if the stressors associated with risk are perceived and experienced by the individual as stressful (Lazarus & Folkman, 1984). The implication is that stress, and by extension risk, is in the eye of the beholder given that, though scientists may define a set of life circumstances as extremely stressful, the individual who lives daily in those same circumstances might consider themselves as doing relatively well (Luthar et al., 2000).

Researchers have encountered similar dilemmas when defining terms such as protective factors and positive adaptation. In early models of resilience, the term ‘*protective*’ was used in some studies to describe characteristics of individuals who by virtue of certain attributes seemed unaffected by adversity, while in other studies the term was used to describe immediate protective effects (Luthar et al., 2000). Garmezy (1971), Rutter et al. (1976), and Werner & Smith (1982) each cite family relationships as having potential protective effects. The presence of protective factors across ecosystems suggests that resilience is not static or particular to the individual. Moreover, Rutter (1987: 317) contends that these variables are ‘*highly robust predictors of resilience*’ and as such they may play a central role in processes underpinning an individual’s response to risk. To this, Luthar et al. (2000: 548) add,

*With accumulative evidence that a particular variable does effect competence levels within a specific at risk group, investigators need to focus their inquiry on understanding the mechanisms by which such protection (or vulnerability) might be conferred.*

The conceptualization of resilience as a process accepts that risk/protective factors, and their effects, are multidimensional, subject to variability across different situations and throughout the life span of the individual, and this is important in relation to TD siblings, as discussed below. Essentially, responses to stress will vary and an individual who manages stress well at one juncture may not react the same way to a different stressor at another point in their life. Rutter (2006) argues that when circumstances change resilience can alter, which suggests that resilience is contingent upon processes and interactions

between the individual and their environment – including for the TD child, proximal individuals within that environment namely, parents.

As relational beings, we bring subjective meaning to bear in all our interactions. The meaning we attribute to an interaction and our resultant response, is mediated by cognitive processes such as perception, which inform coping processes (Lazarus, 2006). These processes are informed by the kind of personal and situational risk/protective variables cited by researchers in various works (Rutter, 1987; Ungar, 2013; Werner & Smith, 1982) and this may be particularly important in the context of ASD.

In ASD research literature that examines siblings of autistic children and assess the TD child's adjustment, there are studies which suggest the potential mediating effects of demographic factors as well as personal attributes, parental support and social support as previously discussed (Hastings, 2003; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Rossiter & Sharpe, 2001). Each of these shapes an array of experiences for TD children in this context, as each has the potential to moderate or exacerbate stressors within the parent child relationship. Researchers contend that some potential mediators are static and cannot be changed such as the type of disability the family are coping with (Abbeduto et al., 2004; Eisenhower, Baker, & Blacher, 2005; Phetrasuwan & Shandor-Miles, 2009), a TD child's birth order (Hastings, 2003), or a family milieu where the family's socioeconomic status is low (Macks & Reeve, 2007).

Related to these considerations is the TD child's attachment relationship to the parent. Secure attachment may facilitate resilience, in that the child's internal working model may be one that will privilege the positive – a healthy view of self and an assumption of good intent in relation to proximal others. If as Lazarus (2006) argues, perception mediates meaning, a healthy secure attachment relationship may allow TD children in stressful or risk circumstances to make meaning from their experiences in a manner that facilitates adaptive rather than maladaptive coping - and who are better positioned to facilitate this than parents?

Parents & family are couched in a far bigger ecological system (Bronfenbrenner 1977). The complex and social microsystem that is family, is malleable and benefits from interventions such as social support as discussed later in this thesis. Targeting situational variables in the ASD home that are amenable to change may be key in considering supports and interventions for TD siblings in this context. Masten (2016: 290) suggests

that, targeting flexible resilience factors ‘...such as effective parenting skills or secure attachment relationships between children and their caregivers’, in strength based interventions for the family, has compelling corroboration in developmental resilience literature. Therefore, in cultivating resilience in TD siblings, it would seem that a strength-based approach to the parent child relationship that enhances protective factors is more effective than reducing risk factors. Rutter (1987: 119) asserts that this has far reaching implications, arguing that reducing negative and increasing positive chain reactions, ‘influences the extent to which the effects of adversity persist over time’.

There are many parallels between common factors associated with resilience in developmental resilience science and ambiguous loss theory. Masten (2016: 291) contends that given this, these theories are ‘highly compatible’. Theories of resilience are informed by a strength-based focus, and may facilitate what ambiguous loss theorist Boss (2006) calls ‘living well’. A framework that particularly emphasises this in the context of families under stress, such as a family in the context of ASD, is Walsh’s (2011) family resilience model which is discussed in the next section.

### ***Family Resilience Theory***

Family Resilience Theory is a strength and competence based family paradigm that provides insight into how some families may cultivate resilience in the face of adversity. Walsh (2011) outlines a family resilience framework which is, ‘a conceptual map’ designed to recognize and target key family processes that may diminish stress and vulnerability in high risk contexts and thereby, empowering families to ‘surmount prolonged adversity’ (Walsh, 2011: 405). Given that ASD is a chronic condition, adversity can be considered prolonged. As a framework, family resilience theory redirects the therapeutic focus away from difficulties in the parent child relationship towards amplifying existing and potential competencies. As a result, TD siblings and parents may become more resourceful and better able to manage future challenges. Thus, the development of resilience acts as a preventative and protective measure for parent and child in the context of ASD.

It is argued that psychological processes that operate within the family are key in terms of resilience (Walsh, 2011). These cognitive, emotional and communication coping strategies are processes, behaviours employed by families to cope with stress (Walsh, 2011) and according to some researchers these rather than the severity of a child’s diagnosis can be

predictive in how a family in the context of ASD will cope (Baker, Blacher, Crnic, & Edelbrock, 2002; Bayat, 2007). Enabling strategies related to functional coping include, optimistic cognitive processes, the constructive management of emotions, and open, empathetic communication. Research strongly indicates that these processes act as protective factors in a family under stress because of a child's diagnosis of autism (King et al., 2006; Scorgie, Wilgosh, & McDonald, 1996). These processes, and how they operate and offer protection for the parent-TD sibling relationship in families with an autistic child, are discussed in the following section.

### ***Family Belief Systems***

According to Walsh (2011), belief systems are at the core of family functioning, and are comprised of attitudes, values, biases and assumptions, which combine to shape and inform emotional responses to events. By default these responses guide behaviour, given that beliefs and actions are interdependent and may result in what is termed 'self fulfilling' prophecy (Rosenthal & Babad, 1985). In the context of ASD, researchers suggest that resilient families have belief systems that facilitate positive meaning making when faced with adversity related to ASD (Bayat, 2007; King et al., 2006; Walsh, 2011), in that they actively chose to be optimistic. Through normalising challenging experiences, resilient families engender a sense of agency and control over crises, learn lessons from adversity and ultimately use their experiences to reinforce family coherence as found by Bayat (2007) and King et al. (2006). In doing this, stress is reduced for all family members. Boss (2006) particularly stresses the importance of comparable processes in therapeutic goals for managing ambiguous loss such as normalizing ambivalence and adjusting mastery.

Research that has examined life for families with autistic children has found that having a child with a disability is not exclusively negative and can in fact have positive 'steeling' effects for a family unit when resilience based coping is employed by the family, particularly if the family is well supported (Tehee, Honan, & Hevey, 2009). One such study by King et al. (2006) examined the belief systems of 16 families in Ontario, with children diagnosed with Autism or Down's Syndrome to gain insight into their understanding of their situation. Findings suggest that the families who coped well adopted three particular types of stance that engendered strength and resilience in the face of adversity: optimism, acceptance and appreciation. Researchers found that pivotal to the

ASD family's adaptive coping was the *'importance of having hope with respect to positive outcomes'* (King et al., 2006: 359). Having hope facilitated a sense of coherence and control for participant parents who could then re-establish a sense of coherence and control for TD siblings *'by thinking differently about their child, their parenting role, and the role of the family'* (King et al., 2006: 363).

Masten (2016: 290) draws comparisons between this resilience concept and ideas of *'adjusting mastery'* found in Ambiguous Loss Theory. The goal of each is to enable the family to *'rehabilitate'* itself and move forward in its changed but irresolvable circumstances. In embracing such perspectives, the TD child and parent can harness a sense of hope about the future and apply some meaning to the difficulties they are faced with. Research with families suggests that, in framing their situation positively, parents can contribute to the resilience of TD siblings, whether their autistic child is high functioning or not (King et al., 2006).

### ***Family Organisational and Communication Processes***

Walsh (2011) also sees flexible family organisational patterns and communication processes as core processes in resilience. Communication processes have the potential to bring clarity to a crisis situation and create a climate of open emotional expression, which facilitates problem solving. In a situation that might face a family dealing with a diagnosis of ASD, this type of authentic communication acknowledges the reality of the situation at hand, informs decision-making, and clarifies future expectations in an age appropriate way for young TD siblings. Walsh (2011) further argues that when family members are not permitted to discuss strong emotions, maladaptive, self-destructive behaviours are often a consequence - and this can have negative consequences for the TD sibling's relationship with the parent.

Through adaptive organizational patterns, the TD sibling and parent can maintain connectedness while bouncing forward as they construct a new sense of normality after encountering adversity. Connectedness is preserved by re-organising patterns of interaction to meet their new reality. Research in developmental psychology shows that such connectedness acts as a protective factor for TD sibling's development (Bornstein, Davidson, Keyes, & Moore, 2013; Cummings & Schermerhorn, 2003; Parke & Buriel, 2006). Through strong authoritative leadership and engaging in help seeking behaviours from extended family and community, parents maintain continuity, and restore stability.

This allows parents to provide security and predictability for TD siblings, thereby safeguarding their wellbeing.

In Ambiguous Loss literature, one therapeutic goal for families is to reconstruct identity and family routines (Boss, 2006) in order to engender optimism, hope and collective meaning. In ASD literature that looks at family resilience in the context of disability, studies show that families who manage to do this report increases in emotional growth and connectedness between parents and TD children (Bayat, 2007; Gray, 2002; King et al., 2006; Scorgie et al., 1996). Scorgie et al. (1996) examined life management strategies among parents of children with disabilities. They found that parents reporting positive relational and personal outcomes that could be described as ‘transformational’ were engaged in cognitive processes such as positive reframing of their circumstances, and organizational processes that saw them locate and maximize social supports to meet the needs of TD children in the family.

King et al. (2006) similarly assert that having a child with a disability can be a positive life-changing experience that spurs families to re-examine and re-frame their belief systems in ways which empower them with a sense of control, motivation and purpose. However, Gray (2002) highlights that this may be a long process for some families as his longitudinal study of parents of autistic children illustrates. While Gray (2002) found that many parents he studied had managed psychosocial adaptations that had resulted in improvements to family relationships, developing these coping mechanisms involved the accumulation of skills and profound shifts in perspective that took a number of years to evolve. This process can be enhanced by the availability of social support, as discussed in the next section

### **Family Resilience, Social Support and the TD Sibling**

Literature that examines ASD, the family and social support suggests that evolving the skills outlined by Walsh (2011) and Gray (2002) may be enhanced when a family avails of social support. Schopler and Mesibov (1984: 297) define formal social supports as those provided ‘*through an organized group or agency*’ and informal social support that spans networks which can include, ‘*extended family, friends and neighbours*’.

The role of a support group in the lives of families raising an autistic child has been explored by Mandell and Salzer (2007). They surveyed 1,005 caregivers of autistic

children to ascertain the benefits for families who engage with support groups. The benefits of a support group noted in the study included, information-sharing and a secure environment in which the parent and TD sibling can offer and obtain support – each benefit underpinned by the fact that all members in the group fully identified with the experiences of the others. The need of parents and TD siblings of disabled children to ‘feel understood’ is noted elsewhere also (Clifford & Minnes, 2012; King et al., 2006). Clifford and Minnes (2012) further found that parents involved with a parent support groups – in the case of their study online groups – used more of the enabling strategies related to functional coping that in turn act as a protective factor for TD siblings in a family under stress (King et al., 2006; Scorgie et al., 1996).

The successful coping of families in the studies above might therefore be understood through the lens of Walsh’s (2011) family resilience theory, and Lazarus and Folkman’s (1984) concepts of cognitive appraisal and coping. Existing research findings illustrate that families of autistic children who cope well, employ cognitive appraisals that allowed TD siblings and parents frame their experiences in empowering ways (Lazarus & Folkman, 1984). This generates family processes that are characterised by beliefs, behaviours, and emotional strategies, as cited by Walsh (2011) as contributing to and building resilience for TD siblings.

Throughout the literature, resiliency is associated by researchers with lower levels of depression, anxiety and maladaptive coping, and higher levels of wellbeing and family satisfaction (Bonanno, 2004; Davydov, Stewart, Ritchie, & Chaudieu, 2010; Jackson, Firtko, & Edenborough, 2007; Kapp & Brown, 2011; Masten, 2001; McCubbin, Thompson, & McCubbin, 1996; Sottile, Lynche, Mealer, & Moss, 2014). Therefore, employing resilience based strategies can benefit families who live in the context of ASD and by extension, support the parent-TD sibling relationship.

## **Conclusion**

### ***The Interface of ASD, Ambiguous Loss, Attachment & Resilience***

The aim of this chapter was to review issues central in existing research literature that focuses on families living with a child who has a diagnosis of ASD. The review explored the experiences of families, how parenting in this context informs interactions with TD

siblings in the family, parental mental health, and the psychological adjustment of typically developing siblings who grow up along with their autistic sibling in the home. This chapter also aimed to review theoretical literature that provides an additional lens through which we might explore interactions between parent and child in this context. As the preceding sections illustrate, research literature on ASD and the family suggests that families experience significant contextual and relational changes when a child is diagnosed with ASD.

Language evolves from epoch to epoch and the language used to explore ASD even more rapidly. The language used in many studies cited here veers toward the medical but the integrity of this review meant replicating findings as they were found. That said, whether we use the term difference, disability or diversity, our understanding of neurological divergence, and how we speak of it is constantly evolving. As socially constructed norms are questioned and as ASD communities advocate for themselves, discourse in this area continues to challenge and expand our thinking. Such thinking is culturally and historically specific so that continued evolution in both language and understanding seems inevitable.

As acknowledged in the opening of this chapter, the dominance of psychological theories in the literature means that exploration of these issues produced a literature review that follows a certain line of thought underpinned by psychology. This review highlights a gap in the literature, namely, a need for research around this issue anchored in sociological theory.

This review suggests two further gaps in the literature. Firstly, regarding parent child relationships, the literature clearly indicates a lack of accounts directly from TD children in Ireland who live within a family with an autistic child. Equally, little is known directly from children about the quality of the parent and TD child relationship in this context generally as argued by Hastings (2014). Numerous existing research studies explore family life and parent experiences related to ASD. We know from documented findings that parents and TD siblings can experience life in this context as stressful. Additionally, we know that mental health issues for parents may develop as a result of this, and this in turn can affect how parents relate to and parent their typically developing children. However, we do not know, directly from TD children themselves, how they experience these issues.

It could be argued that the ‘eclipsing’ of the typically developing child by the autistic child found in some of the literature, that happens insidiously, lost in the detail of daily life



within a busy family, has its mirror image in the research agenda. While children are asked about their views on the relationship with siblings or peers, interestingly in the main, children are not consulted directly about their experiences of their parents by researchers who explore autism and the family. This may hark back to long held views related to children discussed in Chapter One that see the family and parenting as sacrosanct.

Quality of life studies conducted in this area and reviewed here rarely focus on the child's relationship with the parent, which as resilience research suggests, could be contended as one of the key determining factors in the child's quality of life. Some research into ASD and its effects subsume children's accounts with parent accounts so that the flavour of what children have to say about their quality of life is compromised, if not lost completely as they are erased from the research page. As discussed here, there are also those studies that focus on adjustment in particular domains of development, which allow only a snapshot of how children are faring, ignoring the bigger picture, namely, that we are relational beings and by extension, domains of development are largely contingent upon significant relationships in our lives that allow us to 'live well' (Boss, 2006). This fact suggests a second gap in the literature, namely, an understanding of ambiguous loss for the TD sibling related to the parent child relationship. Is loss evident and to what degree? Is a sense of loss inevitably experienced by all children? If this is the experience of some, how might these children be supported?

In a longitudinal study, which looks at development over a life span, Mineo (2017) asserts that Harvard researchers find after 80 years of research that it is our relationships that sustain us and have a powerful influence on our wellbeing over our life span. When a family receives a diagnosis of ASD for one of the children, the resulting ambiguous loss directly affects the relationship of the TD sibling and each parent. The parent the TD child knows, and the family in which the TD child lives change significantly and these changes are experienced directly by the child who is not a spectator but rather a player in the family arena. The literature indicates that typically developing siblings in this context are not acknowledged by researchers undergoing an experience as profound and as life changing as their parents.

Ambiguous Loss Theory may be useful in naming and elucidating the loss that may be experienced by TD siblings connected to the parent child relationship. When present, this frozen grief, a story of '*loss without ending*', (Boss & Yeats, 2014: 63) cannot be resolved and so the therapeutic goal for the individual, according to the authors, must be a move

towards resilience. Resilience researchers identify a triad of protective factors for children that privileges the parent child relationship, noting that it may be one factor that buffers children against the ill effects of risk that may be present in their lives. This relationship has been argued as key to the child's wellbeing. Rolfe (2004: 78) also argues a clear link *'to predictions made from attachment theory about secure attachments as a principal source of resilience'*. Although a child's temperament, genetics, and cognitive development play a part, it is accepted that social-emotional development is a product and process of social relationships (Eisenberg et al., 2006; Parke, 1994), and may be affected by the quality of attachment relationships as previously discussed.

Critics argue that developmental trajectories cannot be predicted in absolute terms based on one interpersonal relationship, given that relationships are fluid and constantly changing over time. That notwithstanding, theories of ambiguous loss, attachment and resilience see family as a primary context providing the relational frame for the child's developing sense of self, others, and the world beyond home. Therefore, the quality of the parent child relationship, and family dynamics are among key factors that can shape the TD siblings development as previously discussed. Common to each construct is that each requires positive, supportive interactions with care givers and significant others in the TD child's life. Therefore, understanding relationships from the TD sibling's perspective and supporting a secure attachment relationship between the TD sibling and parent is arguably critically important. Reluctance to involve children in research has seen the parent child relationship documented in a myopic and limited fashion. Moreover, *'the majority of research in this area is atheoretical ... in the future it will be important to develop research underpinned by well established psychological theories such as coping and adjustment, and attachment'* (Akhtar et al., 2012).

This study, which views the TD sibling's experience of the parent child relationship in this context as central to any intervention designed to support the child, attempts to redress this. The study addresses the quality of this relationship by giving a voice to children's personal accounts of their experience and perspectives. Parents' experiences are also documented to provide another layer, contextualise accounts from TD children, and enrich nuances and shades of meaning in what they have to say. The approach to the research among TD siblings and their families inform the next chapter, which examines the methodology and theoretical frameworks that underpin the study, by identifying the methods adopted to produce the data needed to explore the research questions posed.

# **CHAPTER THREE**

## **THE TD SIBLING, PARENTING AND ASD**

### **METHODOLOGICAL ISSUES**

This thesis presents the findings of a qualitative research study which explores the relationship between typically developing children and their parents living in Ireland, where the family has a child diagnosed with autism. Particularly key to this study, is an understanding of how this phenomenon is experienced by TD siblings, with this understanding gathered directly from TD siblings themselves. To understand this, the research process centralised the accounts of typically developing children growing up with an autistic sibling, in addition to exploring the accounts of mothers and fathers, by using a qualitative research approach anchored within a phenomenological research design. Exploring the issues at hand qualitatively involved demographic questionnaires, in-depth interviews, vignettes, and an interview tool informed by the ‘three houses’ interview instrument (Weld & Greening, 2004) with the youngest participant children.

To explore this phenomenon, engagement with participant children and their parents was informed by utilising a qualitative methodological framework, influenced by interpretivist ontological assumptions and constructivist epistemological perspectives, in order to look at the agency of both child and parent in creating, understanding, and negotiating their experience of their relationship in this context.

This chapter outlines how the aims and objectives of the study have been realised, by describing how the research was conducted and then delineating the methodological approach underpinning data collection and data analysis. Ethical issues, in particular, are highlighted and discussed in detail, relating to all issues such as, access, the research setting, participant sampling, and the interview processes.

As the chapter progresses, the research, research aims, and key questions are addressed first, along with a consideration of the theoretical, methodological, and paradigmatic issues that shaped the research approach. This is followed by a description and justification of recruitment and sampling processes, the participants, the research methods, the analytical approach used, and the ethical considerations related to each.

### **A Biographical Note – managing bias**

McKay, Ryan & Sumsion's (2003) assert that researchers should explore and acknowledge the personal and professional experiences and biases that have brought them to their research project. The experiences acknowledged in Chapter 1 have been subject to constant critical reflection regarding the impact of my background, teacher training, professional practice, parenting status, assumptions and life experiences as an adult sibling on the research questions and the process of conducting this research.

Finlay & Gough (2003: ix) stress 'the inter-subjective dynamics between the researcher and the researched' in order to achieve a deeper understanding both of the stories we are researching and of the part we play in constructing them (McKay, Ryan & Sumsion, 2003). The researcher was acutely aware that reflexivity is a critical process in qualitative research which locates the impact of the researcher's context and subjectivity on the design, data collection, data analysis and presentation of findings. Reflexivity was therefore an integral and consistent part of the entire research process and not confined solely to any one stage of the research process.

Wilkinson's (1988: 23) framework outlines three inter-connected forms of reflexivity that provide useful organising principles for exploring the positioning of the researcher. Firstly, at a personal level, Wilkinson (1988) asserts that the researcher makes visible their individuality, examining how their motivations, interests and attitudes impact on the research process. Subjective factors such as my gender, class, my family of origin status as a sibling and parenting status were all important and relevant. For example, as a adult sibling of a sister with autism, I was conscious of my need to remain aware of any possible over-identification with the children being interviewed. It was equally important that I remained alert to; my years of teaching, my experiences in early years provision and practice and how those experiences had influenced and contributed to my understanding of children, parent child relationships and family dynamics. Those experiences predominantly involved women as primary nurturers who know children best, men as a nurturers in a

secondary role, and children as articulate and aware family members with their own personalities, outlooks and preferences. My experience over the years exposed me to an array of families and the complexity of the parent-children relationship, particularly where the family unit were experiencing an unanticipated situation such as a child with a complex support need. I also became increasingly aware that although I was a parent, my experience of autism was confined to that of a sibling. I began with limited insight into how parents experienced parenthood in this context. All of these experiences made an acknowledgement of the influences of the dominant discourses on parent child relationships vital to focusing my research lens well. Simultaneously I was mindful of my own constructions of autism, motherhood, fatherhood, parent child relationships and family life.

Wilkinson's (1988) second consideration, 'functional reflexivity', refers to the role of researcher, the interactions between researcher and participants and the effects that this has on the research process. Wilkinson (1988) contends that researcher-participant relationships are imbued with inequalities, because is the researcher designs and conducts the research. Acknowledging this as something which could not be completely remedied, efforts were made to minimise its impact, through establishing a sense of collaboration in the interview process with all participants, particularly the children. At this functional level, reflexive practice proved valuable as it allowed my to be continually mindful of the negative experiences of power that some participants had experienced, with unsympathetic GP's, public health nurses, dismissive consultants and subsequently with professional services. The voice of children was a priority. I was committed to providing an empowering experience for them throughout the research process.

Wilkinson's (1988) last dimension is disciplinary reflexivity. This involves a critical appraisal of the potential contribution that the particular research project can make to the broader debates about the subject under study. In this project, the inclusion of children's lived experiences- as reported by children themselves - ringing loudly in a debate that has historically excluded them, made it imperative that I intentionally and actively represented their views - in particular where children's views disputed or called into question conventional understandings of family relationships and parent-child dyads. The potential for findings to contribute to the knowledge base on parent child relationships in the context of ASD, ensured that I remained continuously curious about, and receptive to, new and

challenging ideas - whilst simultaneously challenging assumptions or simplistic tropes about or children, ASD, parenting or family dynamics.

## **The Research**

Rubin and Rubin (2012: 42) assert that research design is simply deciding '*what you want to find out - from whom, where and how – as well as determining which data gathering tools are appropriate*'. The overarching purpose of this research endeavour is to '*find out*' how typically developing children in Ireland experience the parent child relationship in the context of disability. The principal research aim was to elicit, directly from typically developing children, their unique and subjective experiences of this relationship in the context of family life. The intention was to explicate TD sibling's experiences of the parent-child relationship by examining their reports of daily life at home, the ways in which TD siblings perceive that they have their needs met, and the strategies these children describe employing to maintain this fundamental relationship.

The word 'relationship' implies a connection between two people – a binding, continuous association. A relationship does not exist in a vacuum but rather, 'in relationship', with the feelings and actions of one influencing the feelings and actions of the other, each contributing to the climate in which the relationship exists (Bowen & Kerr, 1989). Related to the research question were matters of how the TD child was perceived and experienced by parents, and how the parent-child relationship might be nurtured and supported in a family situation that, according to existing literature, can be challenging (Abbeduto et al., 2004; Eisenhower, Baker, & Blacher, 2005; Phetrasuwan & Shandor Miles, 2009; Woodgate et al., 2008). Therefore, in addition to TD children, interviews were conducted with mothers and fathers with the intention of fulfilling a secondary research aim, namely, triangulating findings to bring to the fore places in which parent and child narratives might intersect in order to achieve a more richly nuanced representation of TD sibling accounts. Consequently, the study looked, not only at participants' experiences of 'childhood' and 'parenting', but also at the context in which these occur, the meaning attributed to such experiences, and how they are understood by participants.

## The Research Design

Interest in this research area was informed by the researcher's personal and professional experiences, the literature review, and through selected texts. Having worked in education for a number of years, both in early years provision and secondary education, and as a sibling of a disabled sister, the researcher frequently had contact with TD siblings and families of autistic children. Together, these readings and experiences helped refine the research questions restated here:

1. How do TD siblings experience the parent child relationship in the context of ASD?
2. Do TD siblings perceive their childhood as being sometimes shaped by ASD?
3. How do parents experience the parent-TD child relationship?
4. Do parents perceive that parenting / the parent-TD child relationship is sometimes shaped by ASD?
5. What experiences do TD siblings and parents identify as influencing their experiences of and the quality of their relationship?
6. Do parent-reported experiences intersect with issues TD siblings identify as important to them?

Miles and Huberman (1994: 10) argue that:

*Qualitative data, with their emphasis on 'lived experience', are fundamentally well suited for locating the meanings people place on the events, processes and structures of their lives: their "perceptions, assumptions, pre-judgements, pre-suppositions", (van Manen, 1977) and for connecting these meanings to the social world around them.*

Considering the nature of the research questions, it was clear that the research was concerned with understanding subjective lived experiences and therefore that the research design would require a qualitative paradigm that facilitated this. Denzin and Lincoln (2000:157) define a research paradigm as '*a basic set of beliefs that guide action*'. Epistemologically, qualitative approaches to research are based in a paradigm of personal knowledge and subjectivity (Van Manen, 1990). Creswell (2007) argues that unlike positivist quantitative approaches, qualitative research methods are not constrained by predetermined categories and, as a result, facilitate a precise focus on issues that are meaningful to participants, thus giving rise to a variety of perspectives.

Given the focus of this study, namely, parent-child relationships, qualitative methods were well placed for understanding the subjective experiences of participant TD children and parents. Relationships are nuanced and fluid and are characterized by a plurality of truths (Fraser, 2004). Quantitative methods that might facilitate the gathering of the statistical details of TD children's lives in this context would be devoid of the detail and nuance in their accounts. Furthermore, it has been argued that qualitative methods in general, reach the parts that quantitative methods cannot reach (Green & Thorogood, 2009), essentially affording the researcher a more holistic, multi dimensional view of participants' experiences.

Interpretivism assumes that enquiry into experiences is not focused on 'reality' but rather on the individual's interpretation of their reality, while theories of constructivism assert that the experience of human phenomenon are socially constructed, not objectively real (Guba & Lincoln, 1989). In opposition to a positivist epistemology that searches for universal 'truths', interpretivist, constructionist perspectives are underpinned by principles that assume individuals are social beings, creating and being created by their experiences and understanding of the world around them, so that knowledge is subjective, contextualized and value dependent (Burr, 1995). Therefore, shaped by interpretivist, constructivist influences, this present research was designed to elicit participants' subjective memories, perceptions, understandings, beliefs, meanings, and feelings about their experiences of the parent-child relationship.

This research was concerned with understanding and foregrounding perspectives of TD children in particular who are living through the experience of having autistic sibling. Given that understanding is at the heart of phenomenology (Dukes, 1984), a phenomenological approach was warranted. Creswell (2007) asserts that phenomenology is an approach to qualitative research that focuses on the consistency of a lived experience within a particular group. The fundamental goal of a phenomenological approach is to arrive at an overarching description of the nature of the particular phenomenon. Creswell (2007: 57) further argues that the study of lived experience, '*describes the meaning for several individuals of their lived experiences of a concept or a phenomenon*', with the phenomenon in this case being the parent-child relationship.



Previous researchers have successfully investigated an array of TD siblings experiences of disability using such qualitative approaches (Miller, 1999; Petalas, Hastings, Nash, & Duff, 2015; Petalas et al., 2009; Sin, Moone, Harris, Scully, & Wellman, 2012). The approach to the research design in this current study had the intention of understanding ‘*the world of human experience*’ (Cohen & Manion, 1994: 36) relying upon the ‘*participants’ views of the situation being studied*’ (Creswell, 2002:8), all of which were central to the aims of the study. A dearth of narratives directly from TD siblings, and inconsistent research findings suggested that qualitative research, which documents first hand sibling accounts of their experiences, justified the use of qualitative methods in this area of research.

The interpretivist paradigm inherent in this study means that findings cannot be definitive. This paradigm assumes that there are multiple subjective interpretations of ‘reality’. The goal working within this perspective was to understand how individuals construct and understand their own reality within their particular social context. Vital to the notion of lived experience is the acknowledgement of multiple, subjective realities that are not static. Consequently, knowledge gleaned from the data cannot be generalized to a population beyond the study’s sample and this is discussed further in the closing section of the chapter. The fundamental purpose of phenomenological research is to reduce individual experiences with a phenomenon to a description of their universal essence (Creswell, 2007), therefore the research approach reported here aimed to generate subjective accounts about a relatively under-researched subject, while also aspiring to achieve a description of its ‘*universal essence*’ in context, as referred to by Creswell (2007).

## **Recruitment**

In total, 35 participants took part in this study. The study employed purposeful random sampling, informed by the research aims and objectives, in order to identify and select individuals especially experienced with the phenomenon of interest (Creswell & Plano Clark, 2010); in this case, parent-child relationships in the context of ASD.

### ***Phase One – The original recruitment plan***

The following is an account of the recruitment plan conceived for the current study, which was partially executed and subsequently supplemented with an additional strategy described later. The original recruitment plan involved accessing sample participants

through a selection of primary schools that have ASD units/classes operating within the mainstream school. These schools were identified from a list sourced online from the National Council for Special Education. A diverse selection of schools were initially chosen, spanning Dublin and rural counties, each with varied teaching philosophies, religious orientation, gender mix, and public or fee paying structures.

Initial contact and discussions took place with gatekeepers; which were school principals, by phone. Gatekeepers were advised of all aspects of the study including the inclusion and exclusion criteria. Subsequently, follow-up telephone calls with gatekeepers took place to further discuss any questions or issues that needed clarification. Following several lengthy discussions and agreement to participate given by six school principals, invitation letters plus information packs for parents were sent by email to the principals. Included were thank you letters, reiterating the study details agreed with them by phone. Finally, hard copy confirmation of the study details, along with invitation letters and information packs, were sent to gatekeepers to be distributed to all parents who had a child attending the ASD class and their sibling attending the primary school.

The rationale for this approach was that gatekeepers were likely to have established positive, trusting relationships with the sample population. It was anticipated that this might aid the recruitment process, as discussed by Creswell and Plano Clark (2010). Hard copy information packs were sent in addition to email so that administrative work for gatekeepers was minimal. Additionally, it was hoped that the support of gatekeepers would contribute to building rapport between potential research participants and the researcher (Brann-Barrett, 2009). The role of the gatekeeper was to facilitate access only.

Interviewees were be chosen solely by the researcher, guided by all available information.

Unfortunately, this is where the original recruitment strategy stalled. After several weeks, there were no respondents. Other researchers have examined barriers to recruitment in research endeavours (Gilbertson & Barber, 2002; Hummers-Pradier et al., 2008; Page & Persch, 2013) and cite time and timing as potentially challenging for busy professionals whose workload sees gatekeeping in proposed research as far down their list of priorities. Having little response from principals on follow-up, and unsure whether all gatekeepers had indeed distributed the information packages forwarded to them by the researcher for parents, a supplementary recruitment plan was devised in order to identify potential participants.

### ***Phase Two – The supplementary recruitment plan.***

According to Morah (2017), social media has gained acceptability and recognition as a powerful research tool for the social and behavioural sciences. Facebook in particular, *'constitutes a large and diverse pool of participants, who can be selectively recruited for both online and offline studies'* (Kosinski, Matz, Gosling, Popov, & Stillwell, 2015: 543). With this in mind, a supplementary recruitment strategy was conceived, namely, that potential participants would be contacted, via closed Facebook pages of existing national autism support groups, and via additional Facebook support groups set up by parents themselves, each of which operate as support and information forums for families who have an autistic child. Closed Facebook pages are completely private and members must apply to the page administrators/moderators for acceptance into the group and once accepted must adhere to a code of conduct that governs interactions between page members. While the sample was ultimately recruited from online forums this is not indicative of families in crisis. Some groups provided support and some social contact. Families were engaged online for a variety of reasons including, social contact, financial information and educational support access information.

Contact via such social media forums also fulfilled the study's inclusion requirements, which mandated potential participants to be linked in with a support group in order to take part in the study. A search of social media identified eight Facebook groups, each closed and some with upwards of 5000 members who were parents of autistic children living in Ireland specifically. These Facebook groups were: Jump Autism Support, Snowflakes Autism Support Group, Gravity Autism Support Group, Autism Mamaí Ireland, Autism Dadaí Ireland, Let's Talk Autism Ireland, Irish Autism Mammies, and Tallaght Parents Autism Support Group. While contact with potential participants would be made online, research conducted with respondents would take place offline.

Via private message on the various Facebook pages, contact was made with page administrators briefly outlining the research study, along with contact details for the researcher. Administrators were asked that the message be posted for parents on the group page if the administrators thought it was appropriate to do so. Interested parents could then

contact the researcher directly for detailed information and discussion. There is no way of knowing which pages posted the call for participants and which did not, as the pages are closed, but subsequently 21 mothers and one father, from various locations around Ireland, contacted the researcher. Although more than one father ultimately took part in the research, they came to it via their partners. Autism Mamaí Ireland has 9500 members, while Autism Dadaí Ireland has 100 members. Wayment & Brookshire (2018) argue that mothers tend to be the primary carers of autistic children in the home. Figures here suggest that, as such, mothers may be more active in online support forums, so this may account for the gendered disparity in responses.

### **Sampling of Families**

Criteria for the inclusion of children, mothers, and fathers in the sample were the same and designed with the respectful protection of participants as paramount. In order to participate in the research;

- Respondents were required to be currently engaged with support services.
- Autistic Spectrum Disorder must have been diagnosed for their child more than 12 months ago.
- The autistic child must have a typically developing sibling aged between six and 12 years old. This sibling would be the participant child only if the child consented freely.
- If the potential participant TD child was currently dealing with other sensitive personal issues because of bullying or educational challenges, they could not participate.
- If the family were currently experiencing other significant stressors because of divorce or bereavement, they could not participate.
- Respondents needed to have a conversational level of English

Initial telephone conversations that took place with respondents discussed all of the criteria outlined above and included discussions of requirements for the participation of TD children given that they would be accessed through their parents' involvement. It was not presumed that all families would be two child households. In the event that there was more

than one non-autistic sibling in the family that met the inclusion criteria, each child would be invited to be interviewed.

Following these early conversations, and despite the fact that many parents wanted to arrange a date for an introductory meeting immediately, all interested participants were asked to consult with their typically developing children before committing to an initial meeting with all interested family members. James et al. (1998) argue that a dilemma which may present when conducting research with children is that children are particularly subject to power relations and gaining informed consent from a child may essentially be distilled to having consent from the parent, which results in assent. To avoid this, interested parents were required to fully discuss the proposed research with their TD child, and only when the child expressed interest in participation would a meeting be arranged.

Subsequently, 19 mothers and 1 father called the researcher a second time. Families who made contact and met criteria requirements were invited to participate. In instances where one parent or child declined participation, research was conducted only with those family members who had freely consented. It was at this point that a specific date and time to meet with interested family members was arranged.

Potential participants who did not meet specified requirements were excluded from the study. Of respondents excluded, five called to say that their TD children did not want to take part in the study, so the family could not participate. In spite of a clear explanation of age criteria, a further two families called a second time who had TD children aged five years old and wished to participate. Despite parents' insistence that the children were 'great talkers' and wanted to be interviewed, the lower age limit of six years old was adhered to. The 6-12 age range was chosen, as research indicated that middle childhood was under researched (James et. al., 1998) and middle childhood in this context even more so (Hastings, 2014). Additionally, adherence to the lower age of six years was considered appropriate, as it is generally from around this age on that children begin to develop a reliable and accurate understanding of events in terms of how they have experienced them (Ireland & Holloway, 1996).

Initially, an informal meeting took place with each family in the family home. The first information meeting allowed the researcher to:

- introduce herself,

- get to know the child and parents a little,
- outline the nature of the study in more detail,
- explain the procedure of the interview,
- explain the limits of confidentiality, and
- give the child and parents an opportunity to ask questions or to address concerns.

Upon arrival, after some initial casual conversation, TD children and parents were given information packs detailing the purpose and nature of study. Information packs included: an information sheet about the study; a questionnaire on basic socio-demographics about the family; a consent form to be signed by the parent; a parental consent letter to be signed which gave permission from the parent for the researcher to ask their child to take part in the study; a consent form to be signed by the child; and a separate form for the family's contact details.

Contents of the information packs were discussed with participants and they were asked to interrupt at any time if they needed clarification or wished to voice concern. The researcher was cognisant of any non-verbal indications that participants may be unsure about participation. Regarding children, Katz, Hershkowitz, Malloy, Lamb, Atabaki, and Spindler (2012) suggest that awareness of non-verbal behaviours such as avoiding eye contact, or nervous fidgeting can alert an interviewer to a child's reluctance to take part in the research process. With this in mind, the information sheet was read with the child and discussed in detail with the child to ensure the child fully understood the contents and wanted to take part. The researcher has an established professional background in working with young children and is practiced in, and aware of, the importance of re-checking with children, that they understand what had been discussed and what the study would involve. Debriefing at this point involved reassuring respondents that they were free to decline participation. Having discussed the study, it was agreed that contact would be made in the following five days to arrange interviews proper should they decide to proceed.

Ultimately, thirty-five semi-structured interviews were conducted with 15 TD siblings, 12 mothers and eight fathers. A total of 13 families took part – six living in Dublin, with the remainder living in rural counties in Ireland. Though all family homes were two parent households at the time of diagnosis, three were single parent households at the time of interview. An overview summary of participants follows.

### ***The TD sibling participants***

The 15 children who took part in the study, ranged between six to 12 years old. Of these there were: three girls aged six years, one girl aged seven years, one girl and one boy each aged eight years, one boy aged nine years, two girls and four boys aged 10 years and finally, one girl and one boy each aged 12 years. Each of the children lived in the family home with one or both parents and siblings. Each child had one sibling diagnosed with ASD, with the exception of one 10 year-old who had two autistic siblings. Among participants, four of the children were younger than their autistic sibling while the remaining 11 children were older; nine of the children had only their autistic sibling, while six had other typically developing siblings also; one participant child had a diagnosis of diabetes.

### ***The mother participants***

The 12 mothers who took part in the study, ranged between 35 to 54 years old. Collectively, the women were mother to 34 children ranging in age from 18 months to 20 years old. Among participant mothers, three of the mothers headed a single parent household. Of these single parent households, one of the mothers reported the father's regular participation – but only in the life of his typically developing child; one reported the father's initial involvement but only with his typically developing children and his ultimate return to his country of origin which resulted in no subsequent participation in the lives of any of his children; one reported the death of the father of the participating child several years prior, due to drug use; three participant mothers were educated to Junior Certificate level, three to Leaving Certificate level and six had a Third Level education; one mother worked full time outside of the home; three worked part-time outside of the home and one of these was also engaged in part-time study; two mothers worked part-time from home; six mothers reported they could not work due to the needs of their autistic child.

### ***The father participants***

The eight fathers who took part in the study, ranged between 35 to 54 years old. Collectively, the men were fathers to 34 children ranging in age from 18 months to 14 years old. All were the biological fathers of the children diagnosed with ASD. Of the fathers, one reported that he was the biological father to the autistic child but not the other typically developing child (participant child) in the family; one reported that, as well as being father to an autistic child, he was also brother to an autistic adult sibling - whose

condition was categorized at the more severe end of the autistic spectrum; two participant fathers were educated to Junior Certificate level and six had a Third Level education; two fathers were engaged in further education in conjunction with full time work at the time of interview; one father ran his own small business. Seven fathers worked fulltime outside of the home while one worked full-time from home.

### ***The Autistic Child***

While they were not participants, the details of the autistic children in each family are included here for added context. There were 14 autistic children, two of whom were siblings. Of 14 autistic children, all had a formal diagnosis of ASD with six of the 14 having a dual diagnosis that included ASD. This means that some of the autistic children in sample families had a singular diagnosis of ASD while others had a co-occurring diagnosis such as an intellectual disability. While the degree of deficit in the autistic children of families who participated varied, the research literature clearly indicates that the type of diagnosis a family receives or the extent of the autistic child's deficits are not predictive of how well a family will cope or the emotional climate in the family home (Baker, Blacher, Crnic & Edelbrock, 2002; Bayat, 2007).

### **The Research Setting**

The decision to initially meet the family at home and subsequently conduct the interviews proper in the family home was largely influenced by the fact that children were participants and it was their accounts that would serve as the cornerstone of the study. This decision was further informed by empirical evidence concerned with how best to ensure free and informed consent when conducting research with children.

Children's participation in research can be significantly affected by the context within which the research takes place (Punch, 2002; Hill, 2006). Hill (2006) asserts that the expectations and norms that children associate with a given context shape children's interpretations and responses to research questions. Furthermore, James et al. (1998) critically argue that much research with children tends to be undertaken in school settings. Initially meeting a child in school may lead the child to believe that the research is somehow connected with school which, in turn, might result in the child feeling that they have to take part because 'it's school' (Kellet & Ding, 2004; Punch, 2002). Therefore, it



was anticipated that meeting and interviewing children at home, potentially reduced the power differential between child and researcher (Collins, Jordan, & Coleman, 2010). Additionally, it was anticipated that, in the safety and comfort of their own home, children would feel free to decline taking part - even at the last minute, if they felt inclined to do so.

### **Socio-demographic Considerations**

From an ecological perspective, a myriad of dynamic variables inevitably come to bear on children’s experiences and outcomes. This fact is acknowledged in the work of several researchers who suggest that variables such as family social economic status, family size, sibling constellations, marital stress, social support, parental mental health, and family processes may each act as potential risk or protective factors for the TD child (Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari 1996; Kaminsky & Dewey 2002; Kovshoff, Cebula, Tsai, & Hastings, 2017; Macks & Reeve, 2007; Quintero & McIntyre, 2010; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006; Verté et al., 2003)

The socio demographic characteristics in the home settings of families interviewed were diverse in several respects as the table at the end of this chapter demonstrates. Factors such as the education level of parents, whether one or both parents worked, the involvement / support of extended family members and the location of the family home often shaped the relationship between TD siblings parent and how it was reported. If participants are viewed on a spectrum they vary hugely; from an unemployed young mother, living in the inner city, with little education and parenting alone, to a working married couple, educated to third level living rurally – with grandparents living next door. The extent to which these factors mediate the parent child relationship is explored in greater detail in the findings chapters.

#### **List of Participant Family Profiles with pseudonyms**

<b>FAMILY INTERVIEWS - CO. DUBLIN</b>		
<b>Ellis Family</b>  Mother: Emer, Age 35-44 Education: Degree Employed: Caregiver in the home  Father: employed outside the home Declined interview	<b>Butler Family</b>  Mother: Liz, Age 35 - 44 Education: Leaving Certificate Employment: Caregiver in the home  Father: Robert, Age 35-44. Education: Professional Diploma	<b>Garvey Family</b>  Mother: Gloria Age 35- 44 Education: Degree Employment: Caregiver in the home  Father: Employed and living abroad Declined interview

**FAMILY INTERVIEWS - CO. DUBLIN**

<p>T.D. Sibling: Eavan, Age 10 attending local catholic primary school</p> <p>ASD Child: Elizabeth, Age 14, attending local catholic secondary – plus ODD, ADHD, Language Impairment</p> <p>Dual Diagnosis: Yes – Diagnosed age 11yrs</p> <p>Mother and Father are separated. No other children</p>	<p>Employed: Outside the home - fulltime</p> <p>T.D. Sibling: Amy, Age 12, attending local catholic secondary</p> <p>ASD Child: Conor, Age 5 – attending local catholic primary school plus ADHD, Sensory Processing Disorder</p> <p>Dual Diagnosis: Yes – Diagnosed aged 2yrs</p> <p>Mother and Father are married – TD participant sibling is not the biological child of Father. No other children</p>	<p>T.D. Sibling: Gina, Age 6, attending local catholic primary school</p> <p>ASD Child: George, Age 5, attending local catholic primary school ASD unit</p> <p>Dual Diagnosis: No – Diagnosed age 3yrs</p> <p>Mother and Father are divorced – family includes 2 other children, Geri, Age 3 &amp; Gary, Age 18</p>
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<p><b>Jones Family</b></p> <p>Mother: Janice Age 25-34 Education: Junior Certificate Employment: Caregiver in the home</p> <p>Father: Unemployed. Declined Interview</p> <p>T.D. Sibling: Joe, Age 8 attending local catholic primary school ASD Child: Jill, Age 3. Attending ASD preschool plus Global Developmental Delay</p> <p>Dual Diagnosis: Yes – Diagnosed 1.5yrs</p> <p>Mother and Father of ASD child separated Father of TD sibling participant child is deceased. No other children</p>	<p><b>Hale Family</b></p> <p>Mother: Helen Age 45 -54 Education: Degree Employment: Inside of the home – part time</p> <p>Father: Hugh 35-44 Education: M.A. Employment: Outside the home - fulltime</p> <p>T.D. Sibling: Harry Age 10, attending local catholic primary school</p> <p>T.D. Sibling: Hilly Age 8, attending local catholic primary school</p> <p>ASD Child: Henry, Age 4 - attending local catholic primary school ASD unit plus ADHD, ADD, ODD Dual Diagnosis: Yes – Diagnosed age 2yrs</p> <p>Mother and Father are married – no other children</p>	<p><b>Andrews Family</b></p> <p>Mother: Denise, Age 35 – 44</p> <p>Education: Leaving Certificate plus Vocational Training</p> <p>Employed: Outside the home - fulltime</p> <p>Father: Employed outside the home. Declined interview</p> <p>T.D. Sibling: Elena, Age 7, attending local catholic primary school</p> <p>ASD Child: John, Age 9, attending local catholic primary school ASD unit -plus ADHD, Hypotonia</p> <p>Dual Diagnosis: Yes – Diagnosed age 3yrs</p> <p>Mother and Father are married. No other children</p>
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**FAMILY INTERVIEWS - RURAL**

<p><b>Kirwan Family</b></p> <p>Mother: Kate, Age 35-44 Education: Degree Employment: Outside home –part time</p> <p>Father: Declined Interview</p> <p>T.D. Sibling: Kyle, Age 11, attending local catholic primary school</p>	<p><b>Lawlor Family</b></p> <p>Mother: Self employed Declined interview</p> <p>Father: Larry, Age 35-44 Education: PLC course Employment: Self employed - fulltime</p>	<p><b>Murphy Family</b></p> <p>Mother: Marie Age 45-54 Education: Junior Certificate Employment: Caregiver in the home</p> <p>Father: Mark Age 45-54 Education: Degree Employment: Outside the home – fulltime</p>
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FAMILY INTERVIEWS - RURAL		
<p>ASD Child: Kim Age 5 - plus developmental delay ASD Child: Karl Age 3, attending specialized ASD unit, attending local preschool</p> <p>Dual Diagnosis: Yes–Kim diagnosed age 3yrs No – Karl diagnosed age 1.5yrs</p> <p>Mother and Father are married. No other children in the family</p>	<p>T.D. Sibling : Lily, Age 6, attending local Educate together primary school</p> <p>ASD Child: Leo Age 8</p> <p>Dual Diagnosis: No – Diagnosed age 6 yrs</p> <p>Mother and Father are married. No other children in the family</p>	<p>T.D. Sibling: Milly, Age 10, attending local catholic primary school</p> <p>ASD Child: Micah, Age 7, attending local catholic primary school ASD unit</p> <p>Dual Diagnosis: No – Diagnosed age 5 yrs</p> <p>Mother and Father are married – one other child in the family, Maggie, Age 14</p>
<p><b>Norton Family</b></p> <p>Mother: Nuala Age 35 – 44 Education: Leaving Certificate Employment: Part time – one day per week out of home</p> <p>Father: Niall 35 - 44 Education: Degree Employment: Full time working from home</p> <p>T.D. Sibling: Ned Age 10 T.D. Sibling: Nell, Age 6, Each attending local catholic primary school</p> <p>ASD Child: Noah, Age 8 Dual Diagnosis: No – Diagnosed age 5 yrs</p> <p>Mother and Father are married – One other child in the family, Nikki, Age 2</p>	<p><b>Farrell Family</b></p> <p>Mother: Fiona, Age 35-44 Education: Degree Employed: Caregiver in the home</p> <p>Father: Frank Aged 45 – 54 Education: Junior Certificate Employment: Own business</p> <p>T.D. Sibling: Fionn Age 10, attending local catholic primary school</p> <p>ASD Child: Fiachra, Age 4, attending local catholic primary school with SNA</p> <p>Dual Diagnosis: No – Diagnosed age 2.5 yrs</p> <p>Mother and Father are married – One other child in the family, Freddy age 14</p>	<p><b>Duffy Family</b></p> <p>Mother: Sue, Age 35-44 Education: Degree Employed: Outside of the home: part-time</p> <p>Father: Derek, Age 35-44 Education: Master’s degree Employed: Outside of the home- fulltime</p> <p>T.D. Sibling: David, Age 9, attending local catholic primary school</p> <p>ASD Child: Dylan, Age 7 , attending local catholic primary school</p> <p>Dual Diagnosis: No - diagnosed age 3.5 yrs</p> <p>Mother and Father are married – no other children in the family</p>

## Data Collection

A total of thirty-five semi-structured qualitative interviews were conducted with members of 13 families. These included 15 children, 12 mothers, and eight fathers. In advance of all interviews, including the children’s, an explanation of the aims and objectives of the study were restated and demographic forms for each family were collected from a parent. The limits of confidentiality, and its application to participants in the study was discussed again in detail with each individual. The issue of informed consent was then addressed and

written consent was secured from each participant. Given that some parents had expressed that they were very ‘interested’ in knowing what their children might have to say in interview, it was also reiterated to participants that no party would have access to another’s interview.

### ***Parent Interviews***

Both mothers and fathers interviews followed the same semi structured interview format (Wengraf, 2001). Given that talking to parents about their parenting may be a sensitive issue, a non-directive approach to interviews was adopted that was conversational in tone. Taking the position that the parent is the authority on raising a family with an autistic child, this process was led by the parents’ recall of their own story, and used probe questions to explore specific topics sensitively. The interviews were semi structured, allowing questions to move from the general to the specific and gradually introducing issues that had the potential to be sensitive. Interviewing in this way also facilitates the use of probe questions to elicit more detailed information or clarify what is being said (Patton, 1990). Initially, the parent was invited to relay how they first learned about their child’s autism and what that experience was like. This led naturally into a discussion of the family and family life. Interviews were participant led throughout, consisting of the perspectives, experiences and concerns of the parent. To ensure uniformity, and in an effort to ensure that all issues were discussed in a relatively comparable manner, a topic guide that listed areas of interest, informed by the research aims and objectives, was prepared. This discreetly functioned as an aide-memoire to shape open-ended questions on occasion.

While several hours were spent with each family on the day of interview, the duration of actual parent interviews varied from 35 to 90 minutes. Mothers’ interviews were each longer than fathers’ or children’s. Given that mothers tend to be primary caregivers in the context of ASD (Wayment & Brookshire, 2018), this was not unexpected. Two fathers had actively prepared for interview and had notes of specific issues they wanted to discuss and points they wanted to make. Although the order of topics discussed changed from interview to interview, the same issues and concerns emerged repeatedly for all parents so that all topics were addressed by each participant. Topics discussed with parents included:

- Their memories of ASD diagnosis and how TD children were told of it.

- Their perspectives on their TD child's response to and understanding of diagnosis.
- Their daily experience of the emotional climate in the home.
- Their daily experiences of parenting in this context.
- Their perceptions of their TD child.
- Their perspectives on their relationship with their TD child.
- Their experiences of family time together.

The interview process became emotional for two particular participants at one point – one a mother and one a father, each from different families. Despite several offers to end the interview, neither participant did, with the mother stating that she wanted to '*be heard*'. Many mothers expressed similar sentiments in that they felt somewhat unseen as a research population in relation to their TD child and were eager to have their experiences and their TD child's experiences documented.

Debriefing post interview involved asking the participant if there was anything further they wished to add, checking in to see how they were feeling and reminding them of the support services available to them should they need them.

All interviews were audio recorded with the permission of participants, using a dictaphone. These recordings were downloaded and listened to immediately after interview and field notes/memos were taken. In accordance with the Data Protection (Amendment) Act, 2003, and university guidelines to good research practice, all files were kept safe and secure on a password-protected laptop belonging to the researcher and to which only the researcher had access (Data Protection Commissioner, 2003; Trinity College Dublin, 2009: 24).

Post each set of family interviews, observations were noted in an informal reflections journal to supplement accounts. Accounts were then transcribed verbatim, and re-read numerous times. Audio recordings were initially stored as non-anonymised data. During the transcription process, the data was anonymised so that all personal and/or place names or identifying characteristics were altered. Any information that might identify a participant was removed or changed. Given the research questions and the very human dimensions to the topics discussed, pseudonyms were used to identify participants rather than numbers, which seemed impersonal. In the findings chapters that follow, words which constitute the experiences shared by participants appear in italics. For clarity, quotations from participants have on occasion been slightly edited to take account of dialect;

however, italicized quotes are a true and accurate representation of the participants' accounts from the interview process.

### ***TD Sibling Interviews***

Prior to children's interview, several parents had communicated their TD child's 'delight' at the thought of a visitor to the home who was visiting specifically to speak with them. Parents explained that usually, visitors to the home were there with regard to the autistic child. This enthusiasm to participate was evident in several child interviews.

James et al. (1998) argue children's ability to competently participate in research. Existing findings show that research methods that are based on children's skills and have a degree of mutuality, allow children to participate in research in ways that are familiar to them and give them a sense of control (Mauthner, 1997). Further, Hill (2006) argues that such approaches ultimately result in an enjoyable research experience for children. Speaking in relation to research with children, Mauthner (1997) considers individual interviews and self-completed instruments to be more suited to middle school children, so particular attention was given to the interview techniques employed in this current study. All pre interview briefings and post interview debriefings employed in adult interviews were equally adhered to in TD child interviews. This was done through the use of moderated age appropriate language and allowing for additional time for any questions from the children.

### ***The 'Three Houses' Model***

The youngest TD children participating in the study were interviewed using a technique informed by the 'Three Houses Information Gathering Tool', developed by social workers Nicki Weld and Maggie Greening in 2003 in New Zealand. The 'Three Houses Tool' is a visual information gathering tool that is narrative in focus and informed by strength based practices and the Signs of Safety approach developed by Andrew Turnell and Steve Edwards in 1999 in Western Australia. This model is primarily used in the course of child protection work. While this research was not concerned with issues of child maltreatment, it was concerned with opening a dialogue with children who, as existing research previously discussed suggests, are dealing with a unique set of challenges. It was felt that the collaborative framework of the model was a way to open a dialogue with children, which allowed the researcher maintain a position of inquiry, while working in partnership with the children to bring their voices to the fore.

Weld (2008) asserts that her primary reason for creating the three houses tool was to address concerns about the absence of children's voices in planning for families linked to child protection practices. Her objective was to bring the voice of children more clearly into this work. The tool is designed specifically for children so that practitioners can access their thoughts, their priorities, their views about what is going on in their world, and what is happening for them from their perspective. Further, Weld (2008) argues that the objective of using the three houses tool is to promote engagement, rapport and conversation with the child, in order to build understanding and learning about the child's world. For the purposes of the current research, it is a tool that influenced the creation of a research instrument to access TD children's inner worlds because it allows them both verbal and nonverbal means of communicating their experiences of the parent-child relationship. Given the research objectives in the current study, this method of communicating with participants allowed the children a degree of control and facilitated mutuality between researcher and child that was cordial but not overbearing. By their own hand, the TD child could quite literally write their story into the research.

The researcher attended each TD child interview armed with coloured paper, pens, pencils, crayons, glue, and glitter. Children had control of the dictaphone so that their sense of agency in the interview process was supported. The child's ability to pause or stop the interview as they needed to was important to the collaborative nature of the work. While working with the younger children, in order to meet them at their level, an explanation of the three houses model and how it would be used took place in age appropriate language. When prompted, the child then chose a coloured page to represent each house. This technique involved the TD child drawing three houses - House of Good Things, House of Worries, House of Dreams and Hopes. Starting with the house of their choice, the child drew people and things she/he would put in this particular house, and then did the same with the other two houses. TD child participants wrote representations of their personal accounts onto the pages helped by the researcher when requested.

This exercise was done with a view to opening up a dialogue with the child, where the child's pictures and commentary were used to explore topics similar to those explored with parents such as the emotional climate in the home, the relationship with mum/dad, their sibling's diagnosis, and fun family time. For very young children, the researcher offered to help them write their words and phrases into the house if they found it difficult. The child's

words were written verbatim. Conversations with the children flowed as this happened and conversations felt less 'interrogative' as a result. The children were quite specific in what they wanted to include in each house, with the youngest children 'decorating' their houses most elaborately.

All younger participant children engaged in this process readily and enthusiastically. Child interviews lasted between 15 – 40 minutes. The shortest child interview took place with the youngest child participant. After 15 minutes talking, she visited the bathroom and the interviewer discerned that she possibly was becoming fatigued. When she returned, the researcher asked her if she would like to finish or continue, and she chose to finish.

### *Vignette*

Having a background in education and having mainly worked with children in that time, the researcher anticipated that children aged 10 years and older might feel too 'grown up' for the three houses tool and so a specific research tool needed to be put in place for these children.

Research into response bias or social desirability bias suggests that, around sensitive issues, individuals may respond to questions in a socially desirable way in order to be seen in a positive light (Edwards, 1957). Given the sensitive nature of the current study's focus, the possibility was considered that older children may be inclined to represent their experiences in a 'socially acceptable' manner, that is, that they might be reluctant to express negative feelings about their situation, especially if those feelings implicitly criticised their parent or autistic sibling.

To address this possibility, a vignette was conceived for use with older child participants. Soydan and Stal (1994) argue that vignettes are effective when they engage the respondent by being relevant to their lives and presenting a situation that they can relate to because it feels real. O'Connor and Hirsch (1999) add that introducing a short vignette during a research interview can act as a break or shift in focus, and this change can invigorate the interview process. With these points in mind, a short vignette was formulated that essentially mirrored what the participant child was living. This vignette was introduced into the conversation after the child had shared some of their experiences.

Starting with open ended questions, older children were engaged in a dialogue that was not dissimilar to the interview process with their parents, but moderated in keeping with their



age. They were initially asked about their understanding of their sibling's diagnosis and this led seamlessly into a discussion of the family and their relationship with their parents. In direct conversation, characterised by probe questions which followed what the children chose to share, the children invariably qualified negative statements with something positive or negated what they had just said by diminishing its importance. It was at this point that the vignette was introduced into the interview process. The vignette was informed by the research questions and read aloud as transcribed here:

*'If you can, imagine that your best friend has just been told that their sibling is autistic. They come to you to talk about this news. What would you tell your friend about what they might expect next. What would family life be like for your friend in this situation? What would the relationship with mum/dad be like for your friend in this situation? How might your friend expect to feel?'*

The child was asked to draw on their own experiences to answer how they might respond to their friend and their answers were used to further explore topics that the children had already referenced. According to Barter and Renold (2000), vignettes have been used in various research disciplines to explore a variety of social issues. Neale (1999) asserts that vignettes can be useful in exploring potentially sensitive topics that participants might otherwise find difficult to discuss. Hughes (1998: 384) similarly argues that it is *'the relative distance between the vignette and the respondent'* that can facilitate this. Such assertions seem tenable given that, when discussing the hypothetical situation suggested by the vignette, the children did not qualify their statements in the same manner. This may be because, as Barter and Renold (2000: 3) argue, *'Commenting on a story is less personal than talking about direct experience, it is often viewed by participants as being less threatening'*.

The use of the vignettes facilitated a level of engagement by the older children that allowed them express an additional dimension to their experiences. They each engaged with the vignette scenario, some even listed events that might occur for their friends – drawn from their own experiences, while others spoke of how challenging life can be in this context. The children were less measured in their responses in discussions related to the vignette.

### **Ethical Issues**

The population taking part in this study were families raising a child with a disability, so for participants the prospect of disclosing personal experiences had the potential to generate distressing recollections. As a researcher striving to explore this area, it was vital

to consider ethical safeguards for all participants, particularly the children (Punch, 2002). The ethics of research concerned with children's life experiences largely focuses on issues related to consent, confidentiality, and protection (Mauthner, 1997; Punch, 2002). With this at the forefront, the research design in the current study was informed by the ethical principles of best practice outlined in the literature that examines these issues.

Participants' dignity and well-being was integral to the integrity of this research. Giving voice to the experiences and views of 6-12 year old children was central. Children were only invited to participate with the consent of their parents. Ethically robust research comprises three fundamental core features:

- ensuring voluntary informed consent,
- the guarantee of confidentiality and anonymity, and
- doing no harm

### ***Informed Consent and Confidentiality***

The research design adopted safeguards for participants across each of the three core features noted above. With regard to a protocol for interviewing children, the research process was guided by Trinity College Dublin, Children's Research Centre Ethical Guidelines (2006), Policy on Good Research Practice (2009), Children First 2011 (Guidance on the Protection and Welfare of Children) and DCYA's Guidance for Developing Ethical Research Projects Involving Children (2012). In addition, the researcher was Garda vetted and also undertook a Child Protection Workshop, anchored in the key principles of best practice in child protection (Children First, 2011) to ensure a clear and thorough understanding of the ethical and safety procedures which must be adhered to when interviewing children.

James et al. (1998) argue that a dilemma which may present when conducting research with children is that children are particularly subject to power relations and gaining informed consent from a child may essentially be distilled to having consent from the parent, which results in assent. However, excluding children from research on sensitive issues may itself be unethical, as children are silenced and remain powerless (James et al., 1998). Bartholome (1996, in Nelson & Reynolds, 2003) asserts that the following elements regarding the assent process and children must be addressed by researchers;

- Help the child reach a developmentally appropriate awareness of the issue,
- Disclose the nature of the child's likely experience,
- Be alert to non-verbal signals that the child may not want to participate,
- Assess the child's understanding and any coercive factors influencing the child, and
- Solicit the child's willingness to take part.

With this in mind, the concept of ongoing consent was pivotal to the research process to ensure that child participants demonstrated that they fully understood what they were undertaking, and freely consented to taking part in the process at all stages.

In accordance with the principles of ethical research as set out by Trinity College Dublin (2009), prospective participants were fully and clearly informed about the background and purpose of this study. In age appropriate language, the child and parent were informed that their participation was completely voluntary, that they could take breaks, refuse to answer a question or withdraw at any time before, during or after the interview, for any or no reason, without penalty. It was explained that findings from the research would primarily be used in a thesis as part of the requirement for a PhD. Participants were also made aware that findings may be published in academic articles or presented at conferences. They were assured that their contribution was entirely anonymous, and that their real names would never be used. Interviews that were audio-recorded (with participants' permission) were anonymised in the transcription process.

The limits of confidentiality, and how it applies to them as participants in the study, was discussed in detail with each individual. As a legally mandated reporter, participants were made aware, both verbally and in writing, of the fact that confidentiality would be necessarily breached in circumstances where a disclosure was made that suggested that they or another person was in danger. Both child and adult participants were made aware of the above issues throughout, and in particular at three junctures – the informal information session with parents and child; at the signing of consent forms; and these issues addressed again immediately prior to interview. It was also reiterated to participants that no party would have access to another's interview.

### ***Ensuring 'No Harm'***

All ethical concerns are underpinned by one pervasive ethical tenet – no harm should come to a participant as a result of participation – either during the interview process or through

dissemination of findings. Mindful of ‘doing no harm’, exclusion criteria cited earlier were in place to safeguard against recruiting families where the current family situation might deem participation inappropriate or stressful for family members. A thorough discussion took place with participants at initial family meetings and prior to interview, to confirm that no family was currently experiencing stressors that might be exacerbated by participation. In addition, the dissemination of findings was discussed, as was the lack of researcher control in how mainstream media might use such findings<sup>2</sup>. While it was intended that this study would not contribute to challenges experienced by this population, lack of researcher control in relation to media was discussed during fieldwork, concurrent with a clear assurance to do no intentional harm. Participants were also advised that the information sheets included contact details for both the researcher and her supervisor so that they could withdraw from the study even after interviews were complete.

Given professional training, in addition to previous experience interviewing children and adults, the researcher felt capable of identifying if any participant was becoming distressed in the course of the interview - and so was ready to adjourn or end an interview where appropriate. In a situation where an interview led to feelings of distress, the researcher was equally prepared to actively support any participant in accessing appropriate help or support such as those offered by Irish Autism Action, Autism Initiative Group, and Autism Speaks. Having worked with children and their families for a number of years, there existed an acute awareness of the importance of the wellbeing of each participant. Participants were engaged with in a respectful and sensitive manner, to establish a supportive and relaxed environment. Deeley and Love (2010) suggest that such an environment may be key in preventing distress from occurring in an interview situation or minimizing it if it does.

With all participant families, Haigh and Witham’s (2015) care protocol was utilized. This protocol was developed for the management of distress in the context of a research interview, in order to respond to such a situation appropriately should it arise. In two interviews where parents became upset, the care protocol was employed and the participants were asked if they wanted to terminate the interview or if they felt able to continue. In both cases, the parents concerned were eager to continue the interview.

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<sup>2</sup> Wakefield et al. (1998) linked autism to the measles, mumps and rubella (MMR) vaccine administered to children. Though ultimately discredited, the findings and aftermath were sensationalized by media over an extended period of time.

'Checking in' with participants continued throughout the interview, even when discernible signs of distress were no longer present.

The planned care protocol for children was equally rigorous. If a child became distressed, the protocol would be to terminate the interview, and ask the child if they would consider talking to an adult they trust (identified by the child). Alternatively, the researcher would offer to do so on behalf of the child if they feel unable to do this themselves. In the event, this did not occur in any child interviews. One child interview was ended after 15 minutes because the child appeared fatigued and when given the option, the child chose to end the interview.

While no payment was offered to respondents for their participation, children did receive a small gift of a 'goodie bag' as a token of gratitude for their having taken part. In addition, a thank you email was sent to parents in the days following interview in appreciation of their time and effort. Several parents responded indicating that no thanks were needed, stating that they were happy that the research community was committed to exploring the issues around autism and their typically developing child.

## **Data Analysis**

Analysing data harvested from interviews was a protracted process, which began when fieldwork commenced. To ensure that the researcher was, 'hearing the data' (Rubin & Rubin, 2012) literally and metaphorically, preliminary stages involved keeping a reflection journal, transcribing audio files, and proof reading them while listening again to the audio file. Hardcopy transcripts were then read and re-read so that emerging patterns could be identified across the complete data set and hand coded via notes in the margins. This was an important juncture in the analysis in that my position as an adult sibling and a teacher of young children, coupled with the research question shaped an inclination towards a child centred focus in the analysis from this point. The data documenting the parent experience of the parent child relationship was sorted and cross-referenced with the children's data. During this stage, codes were sorted and re-sorted under major themes and sub-themes. With the research question in mind, themes that related directly to the child's reported experience were given priority so that some themes such as 'parents' childhoods', were ultimately subsumed into larger more relevant themes related to children's accounts. This

was to ensure that overarching themes reflected issues present in the children's dataset – that is it was the children's accounts that served as the lens to focus parent accounts.

This inductive approach sought to extract significant statements from the data, identify patterns and coalesce them to compile provisional themes related to the research question. This process was anchored in a thematic analysis approach. Braun and Clarke (2013: 178) argue that as a flexible, recognized and accepted method for data analysis, thematic analysis is '*a distinctive method with a clearly outlined set of procedures for the social sciences*'. Adhering to the procedural stages of coding data outlined by Braun and Clarke (2013: 202-203), organizing, coding and recoding the data was a crucial part of reviewing emergent themes. Following these stages, a summary statement of provisional themes, supported by quotes from participants were collated to explicate experiences of participants related to the research question.

When clear themes and patterns became apparent, the data were then entered into NVivo, and subsequently the process of coding and recoding continued until themes were defined and named. Ultimately, a 'thematic map' resulted that exposed the predominate themes in the data and how they related to each other.

### ***Validity, reliability and generalizability***

Braun and Clarke (2013: 278) assert that criteria for evaluating quantitative research are widely agreed upon, and rest on the premise that '*good research is reliable and valid and the purpose is to generalize beyond the sample to the wider population*'. However, they qualify their statement asking, '*Do these criteria apply for qualitative research?*'

The nature and role of reliability in research is debated but there is some consensus around established methods, which can address the issue of reliability and validity in qualitative projects. May (2001) contends that this can be achieved in various ways. Firstly, standardization refers to how a questions are designed, administered and analysed. Oppenheim (1992) explores this arguing that we must rely on the interviewer's skill to approach participants as uniformly as possible - so that interviewees are asked the same questions, with the same meaning, in the same words and sequence. Secondly, reliability is concened with the likelihood of other researchers reproducing the research and producing the same results with different groups at different times, which bolsters confidence in the original findings. Validity, the other side of reliability, is achieved when the research

instrument determines what it was proposed to determine (May, 2001). Regarding validity, Braun and Clarke (2013: 280) argue that the quantitative construct of '*ecological validity*', which addresses the relationship between the research and the 'real world', is relevant to qualitative study in that qualitative studies gather data in ways that are less clinical and more related to the real world. Subsequently, such qualitative methods use measures that can capture 'realities' – conceding that the 'realities' captured constitute multiple voices related to the topic under study, and specific to the context and participants.

Qualitative researchers and quantitative researchers may address these issues in different ways. These differences mostly centre on the reliability and validity of measures employed by quantitative research, as opposed to the in-depth personal accounts of lived experience sought by qualitative research in order to understand subjective meaning (Winchester, 1999). Kronick's (1989, cited in Rubin & Babbie, 2005: 202) criteria for evaluating the validity of qualitative research can be usefully applied here. Firstly, Kronick states that validity is achieved with 'internal consistency', where the interpretation of one selection of the data is largely consistent with other parts, so that the developing argument is 'internally consistent'. In this work, continual reflection and analysis of the data involved visiting and revisiting transcribed interviews to secure this 'internal consistency'. Internal consistency was secured with findings from each interview set broadly consistent with each other. Secondly, Kronick (1989) asserts that all presenting evidence should be taken into account when arriving at an interpretation of the data. Thirdly, interpretation should be compelling in light of the evidence, something that this researcher endeavoured to do in analysing and interpreting the data. Finally, the interpretation needs to be meaningful, make sense and contribute to our knowledge of the phenomenon under study, something Winchester (1999) asserts relies, not on the power of generalisation, but rather on the ability of the research instrument to contribute to meaning, explanation and understanding.

Consensus has not been reached on the nature and role of reliability in qualitative research, but there are a number of accepted ways in which the issue of reliability can be addressed, some of which were employed in this study. According to Patton (1999), triangulation can be understood as the use of multiple data sources in qualitative studies, the results of which can contribute to a more comprehensive understanding of a phenomenon. Triangulation compensates for the limitations of any one method, thereby counteracting biases and fortifying the validity of the findings (Greene et al., 1989). Triangulation compares

information gleaned from data to establish if there is corroboration; in other words, it is a *'process of qualitative cross-validation'* (Wiersma, 2000: 45).

In the current study, it was anticipated that triangulation could contribute to understanding the phenomenon under study, namely, the experience of the parent child relationship in the context of disability from the TD sibling's and parents perspective. Merriam and Tisdell (2016: 245) state that options for triangulation include multiple data sources. In the present study, data derived from multiple data sources, i.e. child accounts, mother accounts and father accounts, facilitated more diversity of accounts therefore enriching and adding context to participant reports. It was anticipated that diversity would ensure a more expansive look at children's experiences because findings could be corroborated, potentially increasing the validity and reliability of the data. Where findings converged, they could provide a credible contribution to the understanding of the parent child relationship in the study at hand. In addition, the purpose of triangulation in this study was to develop a comprehensive and expansive account of the parent child relationship that would also highlight contradictory and opposing views where they might exist.

Other indicators of reliability in qualitative research in general and in this current work is member checking, or the verification of the accuracy of the researcher's understanding and observations. Consultation with the research participants took place during both initial telephone conversations, first meetings as described earlier, and then at the interview proper. During all phases, particularly this latter phase, clarification was sought and participants were given opportunities to clarify and elaborate on the points they were making so that their lived experience as reported, was clearly stated and understood. Debriefing after interview bolstered this.

Finally, May (2001) advocates reflection on the research in terms of 'representativeness', or the extent to which the sample is representative of the population. An important feature of participants deserves consideration here. In accessing the sample of families who took part in this research, on-line support groups were central. Arguably individuals involved with online support groups may be struggling more than the general population. It is acknowledged that this is a vulnerable and 'hard to reach' population, and the author further acknowledges that she does not assume that participants are representative of the population of families in Ireland experiencing life in the context of ASD. Nonetheless finding may have 'transferable' power, in that the key findings or 'lessons learned' may likely be applicable in similar settings or populations (O'Leary, 2005).



Sandelowski (2004) asserts that qualitative research results have the potential to be generalised beyond the sample researched, but in a different way to quantitative results. Lincoln and Guba (1985) use the concept of ‘transferability’ to make the same argument, contending that pivotal to enhancing the transferability of a qualitative study results is the extent to which a study specifically describes context, participants, setting and circumstances. They add that, if a study is detailed enough, the reader of the research can determine whether the detail of the qualitative study mirrors other contexts and settings enough to be applicable to other populations.

With this in mind, the current study provides extensive detail on how the study was conducted, the context and the participant families who participated – all within the confines of anonymity and confidentiality requirements. Although the sample was relatively small, it was anticipated that the data gathered in this study would contribute to existing knowledge of how the parent child relationship is experienced in a family where one of the children has a diagnosis of ASD – a previously under researched topic (Hastings, 2014). Winchester (1999) argues that rather than generalisability, such meaningful contributions rest upon the ability of research to augment meaning and understanding related to the phenomenon under study.

### **Limitations and Challenges of the Study**

Having outlined the scope of this study in Chapter One, this section looks at methodological limitations of the study as they emerged throughout the fieldwork experience.

One of the early limitations of the study arose from the difficulties experienced in accessing the research population using the original recruitment plan as discussed earlier in Phase One of the recruitment strategy. This concerned the limited control over gatekeepers and uncertainty around whether information had been distributed to potential participants as agreed. A significant amount of time was spent in communication with school secretaries and principals; printing and posting information packs and letters; and follow up phone calls to move the process along, all of which yielded little. As a result, the time allotted to conduct field work was compromised given almost three months passed where little happened regarding recruitment. This resulted in a time pressure to conceive and

execute an alternative supplementary strategy to secure participants; this had not been anticipated.

This limitation was remedied, to some extent, through the supplementary recruitment plan outlined earlier. While the response to the online call for participants resulted in respondents, there was a clear limitation in that respondents were primarily mothers with only one father expressing initially interest in participation. While eight fathers ultimately took part in the research, this low number is a clear limitation of the research. Although accounts from eight fathers cannot be generalised to the population of fathers who parent in the context of ASD, their individual accounts were compelling and diverse – each serving as a window into their life that potentially lends a greater depth of understanding to the issues under study. Equally, the sample size overall in this study is relatively small. While there are limitations in extrapolating from small samples, data saturation was achieved in the final interviews did not expose topics or concerns that had not previously been mentioned by participants.

A second limitation of the study is that the methods used were essentially self report measures and are not easily verifiable. While triangulation of accounts addressed this in a limited way, research into response bias or social desirability bias suggests that, around sensitive issues, individuals may respond to questions in a socially desirable way in order to be seen in a positive light (Edwards, 1957). Given the issue of parenting that was at the heart of the research, and considering occasional contradictory accounts of parenting offered by parent-child dyads, it is possible that parents and children were subconsciously selective in their disclosures. Related to this, the children interviewed were very young. Revisiting the children for a second interview may have potentially yielded more data from them but doing this may not have been ethical or manageable. On mature reflection, a decision was taken not to pursue this, given the subject matter and balancing the children's participation with the ethical tenet of protection from harm.

A third limitation of the study is that it does not account for longitudinal change in children's perspectives of their relationships to parents over time. Relationships are not static. They evolve and grow in various ways so that a child's experiences and their reporting of those experiences at middle school age may change as they grow into adolescence and adulthood. As demonstrated in the current research, parent child relationships are dynamic, subject to contingency and negotiation. This research

acknowledges these assumptions, without presupposing a definite or definitive experience fixed in time and space.

A final limitation of the study was the lack of prior research studies on this topic. Tentative comparisons were drawn in the literature review between international studies of siblings of autistic children and siblings of children living with other chronic conditions such as Down's syndrome or cystic fibrosis. Studies on the experiences explored here, namely, the parent child relationship as experienced by typically developing children living with an autistic sibling in Ireland were notably absent. That notwithstanding, findings here do echo elements of a number of studies which look at experiences of siblings of chronically ill children in a general way, as discussed previously in the literature review.

## **Conclusion**

This chapter has presented a descriptive account of the methodological concerns related to this research project. It outlined theoretical, epistemological, and ontological perspectives which informed the research design devised to answer the research question. The recruitment of participants, data gathering methods, and data analysis have been described and justified. Ethical considerations, issues of validity, reliability, and generalisability have also been considered, informed by the literature related to these issues.

The fieldwork for this qualitative study was conducted over a 12 month period and involved 35 participants – 15 children, 12 mothers and eight fathers – each from families who are raising a child diagnosed with autism. Fieldwork resulted in a significant quantity of qualitative data which were analysed with the support of Nvivo computer software. Chapters Four to Six present and discuss the findings that emerged from the data analysis in the context of the literature reviewed earlier.

# CHAPTER FOUR

## DIAGNOSIS AS THE CATALYST FOR ‘A FOREVER CHANGE’

The findings that follow are harvested from the research study outlined in Chapter Three. This chapter is the first of three that presents findings drawn from sibling and parent narratives which give an account of participant experiences of having a child in the family diagnosed with autism. Thirty-five interviews were conducted with typically developing children, mothers, and fathers. The participant accounts of their lived experience are augmented by field observational notes taken by the researcher before and after the interview proper and demographic information about each family gathered from participant parents prior to interview.

Thematic analysis identified overarching themes evident across all participant groups, suggesting the key experiences that contribute to TD children's understandings of the parent child relationship are: Diagnosis as a catalyst for a ‘Forever Change’, Parenting Amplified, and Childhood Interrupted.

The first theme ‘Diagnosis as the catalyst for ‘Forever’ Change’, is the subject of this chapter and encapsulates the experience of both the children and parents who participated. This theme is important because in all findings that follow in this and subsequent chapters, it is the enormous change to family life as a result of diagnosis that informs how the parent child relationship unfolds and is experienced by TD siblings. The theme is derived from the words of a participant child and a mother, each from different families, and each of whom concisely articulated what all participants had expressed in some form. All participants spoke of the slowly dawning realization that diagnosis meant that life would never be the same again. Families reported that life had ‘changed, changed utterly’<sup>3</sup> and attending this realization for the majority of participants was a sense of vindication, uncertainty, loss, fear of the unknown, tempered by hopefulness for the future.

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<sup>3</sup> Easter 1916. W.B. Yeats

The chapter progresses from participant parents' early concerns, to their initial experience of, and feelings about, the diagnosis. Parent accounts are presented first to contextualize accounts from TD siblings that follow. This chapter looks at how culturally constructed beliefs about childhood, motherhood and fatherhood informed how diagnosis was understood and managed by the family. Additionally, it explores diagnosis in relation to the typically developing participant child in the family by examining; if typically developing children were told about the diagnosis, who it was that told them, how diagnosis was explained, and when they were told. Finally, the chapter examines how typically developing children in the family report their experience and understanding of their sibling's autism diagnosis.

The first section of findings relates to participant parents' memories, just prior to and around the time they received a diagnosis of ASD for their child. Accounts move from parents' early concerns to the disclosure of diagnosis by professionals – and then to the parents' subsequent disclosures to TD siblings in the family. Much existing literature explores autism and the family in isolation with the parent – asking questions about parents' experiences of diagnosis only, particularly mothers, as highlighted in the literature review.

Explorations of the all-encompassing reach of diagnosis in relation to typically developing children in the family, specifically their relationship with their parents, is notably lacking in extant research findings (Hastings, 2014). With that in mind, this study approached this subject so that children were also asked about their understanding of the diagnosis and their feelings about it. The ways in which reported experiences of diagnosis relate to the parent-child relationship are discussed here and in the chapters that follow.

### **An Elusive Diagnosis**

The trials and stresses often associated with pursuing a diagnosis of autism for a child are well documented in research literature. While accounts are not exclusively negative (Carlsson et al., 2016), previous research has found that securing a diagnosis of Autism Spectrum Disorder can be a disempowering, stressful, and a slow process, the experience of which can affect how parents cope with the diagnosis once they ultimately receive it (Crane et al., 2016; Potter, 2017; Siklos & Kerns, 2007). As noted elsewhere, qualitative

studies that explore family experiences note the multitude of feelings parents encounter once autism is confirmed - initial relief can transmute to anger, grief, fear about the future, and sadness for the diagnosed child (Nissenbaum et al., 2002). In an Irish context, given these considerations, Harnett (2007) recommends procedures for families - *'Informing Families, National Best Practice Guidelines'*, to minimize distress for a family when disclosure of a diagnosis takes place (Harnett, 2007). Harnett's (2007) guidelines suggest that the optimal disclosure protocol for a family should thoughtfully take account of; setting, what family members are present, sensitive communication, and should direct the family towards information and support. For some families in the present study, their experience of diagnosis bore no resemblance to recommendations contained in these guidelines, while some had a relatively positive experience that reflected such protocols. This finding thus suggests a lack of uniformity in how a diagnosis of ASD is disclosed to families by practitioners in Ireland.

Regarding pre-diagnosis, participant parents in this study can be categorized as belonging to one of two groups as described in the work of Ryan and Salisbury (2012), namely, *'passively concerned'* parents or *'actively concerned'* parents. In a small but diverse qualitative sample of parents, Ryan and Salisbury (2012) define passively concerned parents as those who reported that they had noted atypical behaviours in their child but did not take their concerns to a professional, with some waiting up to six months to do so. Conversely, actively concerned parents were those who recalled noting concerns and bringing them immediately to the attention of a medical practitioner to have them then refer the child for further assessment.

In relating their experiences of diagnosis, participant accounts in the present study similarly suggested that parents could be classified as passively or actively concerned parents, as narratives unfolded. Socio demographic characteristics became relevant in this process. It became clear that parents whose career or educational pursuits had brought them into contact with issues around disability were sometimes quicker to identify atypical behaviours in their own child. Two mothers had worked with autistic teenagers and adults while one father, has worked closely as a therapist with younger autistic children. Each reported that these prior experiences informed their personal subsequent experience and how it was managed. While all experiences were unique, several participants recalled the start of their journey was marked by small, niggling but persistent initial concerns about

their child that they could not quite name or pinpoint and these worries were not shared with TD children in the family.

Participant father, Ciarán, described this feeling as follows, '*something was not right, but we didn't know what it was*'. Passively concerned parents like Ciarán remembered adopting a 'wait and see' approach and did not recall immediately addressing anxieties with a health professional. Passively concerned parents reflected that they did not immediately fully grasp the significance of their worries, especially if this was their first child and despite, for some, their previous experiences of parenting. Some parents recounted how they considered different explanations for their child's atypical behaviours such as a language problem or a hearing difficulty because these were the discernible behaviours that presented.

Despite her professional acumen and prior experience of autistic adolescents participant mother, Fiona, reported that, although she suspected autism, she wanted to be wrong and so considered alternative explanations for her child's behaviours. Fiona remembered:

*'... he had actually excelled in every area. He spoke at five and a half months and I had it written in his baby book - 'Dada', 'Mama, 'tata' ... then at 13 months -13 and a half months ... the kids off the road came in - young kids, and I just - it just struck me that when they came in they were calling him that he didn't turn around. But it happened like that ... over night. I said to my husband did he always do that? And he said 'do what?'. I said he didn't turn around ... and he said 'Don't even start!' and I thought ... maybe he was deaf but I knew in my stomach he wasn't deaf, you know?'*

Parents frequently articulated experiences similar to this one reported by Fiona. Many parents considered a myriad of explanations before countenancing the possibility that the issues for their child were related to ASD. Parent accounts indicated that it was not unusual for speech and language therapy or a hearing assessment to act as the catalyst that started the family's journey towards the sometimes, elusive diagnosis of autism.

Conversely, actively concerned parents reported that they immediately consulted with district nurses and general practitioners once they had noticed issues such as delays their child's language or the child's disinterest in any kind of interaction with others (Ryan & Salisbury, 2012). Of actively concerned participant parents, three mothers in the current study stated they had worked in areas that ensured their knowledge of children with additional needs was extensive, and so they brought this expertise to bear on their personal assessment of their child. One mother reported she had worked with troubled teenagers, a second, Gloria, had '*worked with autistic adults before I had the children*'. The third, Kate,

was a resource teacher in a secondary school who said that regarding diagnosis, she knew where to go and what to do and felt, ‘... *lucky because I knew all of these existed through my own work*’. One actively concerned father, Niall, had an adult sibling who was autistic and so, similarly, he had some insight into pursuing a diagnosis and securing supports for his child.

For several participant families, it transpired that one parent was actively concerned while the other was passively concerned. Participant mother, Sue, described the stress her suspicions of autism caused in her relationship, as her husband, Derek, responded to her concerns about autism by arguing ‘*Sue, you are just looking for it!*’ Although Derek’s professional life ensured that he was familiar with autism and autistic behaviours, he reported his reluctance to consider autism as an explanation for his child’s behaviours. The move from passive to active concern often resulted from one parent persistently sharing their worries with the other parent. Participant father, Ciarán, admitted ‘*Claire always knew there was something not right*’, but he stated that initially he had not been convinced. Similarly, Fiona recalled the instant that she moved from uncertainty to absolute clarity, explaining the moment as follows: ‘*He’s autistic ...that’s actually how it went. I knew it. I said it to my husband. He nearly lost his mind because he said to me ‘Just stop now!’*’

Despite this early variance, once the process was underway, all participant parents described a long and sometimes arduous road to diagnosis, resonating existing studies (Crane et al., 2016; Howlin & Moore, 1997; Keenan et al., 2007; Siklos & Kerns, 2007). In their research with 1300 parents of autistic children, Howlin & Moore (1997) report that, despite 50% of parents identifying concerns with their child by the age of two, only half of those children have a confirmed diagnosis by the age of five, while the remainder experience several additional referrals and various delays before a firm diagnosis is finally rendered.

In the present study, research participants reported experiences of delay that were reflective of such literature. Participating family experiences of this were diverse. The main challenges in securing a definitive answer regarding their child’s behaviours were recalled by parents in this study as: misdiagnosis, such as an initial diagnosis of ‘*sensory processing disorder*’; long waiting lists for assessment, ‘*we couldn’t get an assessment for two years*’; and difficulty accessing child services, especially if they lived rurally where services were reported by parents as being ‘*somewhere in the county*’. Parents related these



experiences as stressful, frustrating and worrying, with one mother, Claire, describing it as, ‘a long, long, long process’. This is consistent with the literature. Very representative of

*‘With the HSE, the problem we were having was that everything was, ‘I will see her the next time’ and in 2 years time she will blah, blah ... and then she was too old for one thing and too young for another’.*

Crane (2016: 158) report that parents wait 3.5 years between first contacting a healthcare professional and receiving a formal diagnosis of ASD for their child. Moreover, they note that these findings demonstrate that there has been little reduction in diagnostic delays since Howlin and Moore’s (1997) survey.

During this waiting time participants recounted how family life necessarily excluded TD children and revolved around appointments and consultations, with a view to getting a diagnosis for the child who was the focus of their concerns. Parents described regularly trying to be proactive to speed the diagnosis along. Participants recalled searching social media support groups such as ‘DCA Warriors’ or connecting with ‘Autism Mammies’ on Facebook<sup>4</sup>, in the hope of finding information that might benefit the family in this process. Others relayed how they paid privately for assessments, behavioural therapies, or speech and language therapy, in efforts to establish early interventions that might benefit the child while waiting for a confirmed diagnosis. As Ciarán explained:

*‘We went and actually - privately just to put it on the fast track, because we realised it was going to be another year or two years and that this period might actually cause more delay and more difficulties for her and for us’.*

Consistent with existing studies, stressors during this time were often reported by the parents as being experienced as something only they could understand (Carbone et al., 2010; Cashin, 2004; Keenan et al., 2007; O’Brien, 2007). Parents recalled that extended family and individuals outside of the family did not understand their concerns about a possible diagnosis of ASD. This finding is supported by research literature that finds families repeatedly report a sense of isolation and coping alone in this situation (Cashin, 2004; Gray, 1998, 2002). Woodgate et al. (2008: 1075) cite ‘living in a world of our own’

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<sup>4</sup> DCA Warriors is a public Facebook page with over 22000 members. It is a forum where parents of autistic children share their experiences of securing domiciliary care allowance for their child. Autism Mammies pages are multiple and are similarly set up to provide a forum for mothers to share advice and experiences.

as the essence of parent experiences. Given that 11 of 15 of participant children were older than their ASD sibling, the children too lived to varying degrees, in an atmosphere marked by uncertainty and distress yet parents' concerns were not shared with them.

Opperman & Alant (2003: 441) stress that the demands of raising an autistic child affect, not only parents, but also extend to the typically developing children in the family also and this can begin to happen even prior to formal diagnosis. At the early pre-diagnosis stage in the family's journey, parents in the current study remembered how the typically developing child's relationship with the parent was already being shaped under the weight of autism. Parents recollected, as has been found in previous research studies, how the stresses associated with diagnosis came to bear on typically developing children in the family, regardless of their age (Opperman & Alant, 2003; Vermaes et al., 2012) as their needs began to be placed second to the needs of the autistic child. In the following quote, one mother, Emer, described what could happen in the home for her TD child from as early as 18 months old:

*'Going to Speech & Language therapy ... Eavan's nap was impacted ... Elizabeth's needs were being put first ... I was really trying to accommodate Eavan but, in the end, Eavan had to be flexible and work around Elizabeth's schedule...'*

Other participants described the typically developing child's activities being postponed or abandoned for the same kind of reasons. Invariably, appointments and consultations for the child that concerned the parent were prioritized above extra curricular or leisure activities for the TD child. One particular parent spoke of a seven year period that was characterized by waiting lists, appointments, testing, misdiagnosis and re-diagnosis that saw her typically developing child on the fringes, because her focus *'was all about'* her autistic child. Throughout this pre-diagnosis period of time, parents acknowledged the relegating of the typically developing children in the family as an unavoidable reality that they felt powerless to change. They recalled that they were consumed by finding an answer about the child who was the focus of their anxieties.

Diagnosis of a chronic and lifelong condition such as autism is life altering. As a parent, if the diagnosis pertains to one of your children, this is arguably this is even more so. A diagnosis of autism is marked by the ambiguity inherent in the condition, and the research tells us that the only certainty for families is that life is irrevocably changed for all family members (Hutton & Caron, 2005; Keenan et al., 2007; King et al., 2006). King et al. (2006) assert that these changes go beyond the practical so that families reassess even the

emotional and spiritual elements of their life together. Parents in this study reported that the ultimate diagnosis of autism, coupled with the ambiguity regarding prognosis that characterizes the autism spectrum, made them feel that life would never be the same again. For participant families in the current study, this profound realization was reported as being imbued with the unknown - attended by fear, hope, and every feeling in between.

Accounts of their experiences around diagnosis were testament to the unavoidable ambiguous loss that can occur for a family, when told they are that the child they have, though still here, is not the child they thought they had. O'Brien (2007) argues that Ambiguous Loss Theory provides a framework with which we can understand family's experience of diagnosis and the changes that occur in its wake. Boss and Couden (2002) argue that various mechanisms operate when ambiguity is central to a diagnosis. They note that ambiguity engenders a sense of helplessness, and prevents the reorganisation of family roles so that the individual may become predisposed to depression and anxiety. Given that ambiguous loss is characterized by the absence of the customary markers of loss (Grainger, 2011), the family's distress and confusion remains unverified and this can be psychologically exhausting for those involved (Boss & Couden, 2002: 1353).

Participant parents in the current study reported the type of experience referred to above and communicated how their autistic child, though physically present was psychologically absent in many respects. Several parents stated their belief that this coexisting absence and presence ensured that the family's loss remained indefinable and their grief irresolvable (Boss & Couden, 2002; O'Brien, 2007). One mother, Marie, described the dawning of this new *'forever'* change for her family as follows and explained:

*' There were so many feelings ... a whole lot of the family dynamics were going to change forever. It wasn't just the terrible twos that there was an end to. This was just a forever ... '*

Participant parents' narratives of the confirmed diagnosis of ASD for their child were subjective and retrospective. Six of 13 families reported receiving a dual diagnosis for their child, meaning autism occurs with an additional condition such as an intellectual disability, epilepsy, or Attention Deficit Hyperactivity Disorder. When ASD occurs with an additional disability, research findings tell us that parents have higher levels of stress, depression, and anxiety when compared to the parents of children with another disability or parents of typically developing children (Phetrasuwan & Shandor Miles, 2009; Plant & Sanders, 2007; Woodgate et al., 2008). The family may struggle, coping as they are with

two separate conditions rather than one. The stress inherent in this was evident in all parent accounts – however it should be stated that the severity of a child’s diagnosis is not consistently correlated to how a family will cope (Baker, et al., 2002; Bayat, 2007). This fact too was borne out in parent and child accounts.

The relevance of the families socio demographic characteristics became apparent as accounts unfolded and this is explored in the chapters that follow. With reference to family demographic illustrations contained in this thesis, the juxtaposition of two families in this study illustrate Baker, et al., 2002; Bayat, 2007 findings clearly. The Duffy family, reported that they had a child with significant behavioral and sensory needs. The autistic child had one sibling who was older. In a rural setting, their home and gardens provided ample space to meet their child’s needs. This was bolstered by the reported support of extended family who lived next door and the knowledge base of one parent who was educated and experienced in issues pertaining to autism. They reported stress levels that were largely manageable. Both TD child and parent reported on their relationship and sibling relationships as predominantly enjoyable and satisfying.

By contrast, the Garvey family experience was markedly different. This family was reported as being headed by a single mother whose home was located 20 kilometres from any extended family. The autistic child had moderate behavioral and sensory support needs. The autistic child had two siblings living in the home – one older and one younger. The family home was on a housing estate with a busy road to the front and a small garden to the rear. The mother reported that she did not work outside of the home. She also reported that while previous work experience in a setting with autistic teens was an asset in terms of her knowledge of autism, her day to day existence was fraught with stress as she felt ‘trapped’ and unsupported. Both the parent and TD child in this home reported stress levels that felt unmanageable. The TD sibling reported assuming a parental role with her autistic brother and described home life as ‘*monkey madness crazy*’

Such diversity of experience also echoes arguments about neuro diversity which posit that it is not the extent of the support need that determines outcomes but the social framing of disability and the supports available to those in need of support.

Whether the diagnosis was one of stand alone ASD, or a dual diagnosis that included additional issues, some common themes were repeated in participant narratives. An examination of their memories suggests parents' beliefs about their typically developing children and parenting in this context were informed by their own experiences of childhood and how they understood their role as mother or father. As is found in existing research, in the current study, participant beliefs about parenting seemed heavily saturated in cultural ideals for mothers, fathers, boys, and girls. For participant mothers particularly, culturally informed beliefs about what authors call the *'ideal mother'* (Mesman et al., 2016) were very evident. Parent narratives imply that such beliefs informed how participants received and processed the diagnosis. This was apparent in the kinds of responses to diagnosis which parents reported allowing themselves. It also was evident in how parents recalled imparting the news of diagnosis to TD children in the family, as the following sections illustrate.

### ***Diagnosis - Experiences of Mothers***

Focusing on their experience of diagnosis, participant mother narratives suggested they were informed by culturally shaped ideas that see *'ideal'* mothers as instinctively all-knowing, instilled with an innate sensitivity when it comes to each one of their children (Mesman et al., 2016). Regarding this view of mothering, Mesman et al. (2016) found that this sensitive responsiveness to the child, a key construct in Attachment Theory, almost universally underpins maternal beliefs about *'ideal'* or good mothers. That a 'good' mother knows or should know the unknowable was a belief espoused often by mothers who took part in this study.

Among participant mothers in the present study, nine of 12 mothers exhibited this sensitive responsiveness to some extent. They each expressed that they had experienced a maternal sixth sense – a *'knowing'* or *'feeling'* a long time prior to a formal diagnosis, that something was amiss with their child. Many reported this feeling as emanating from their previous experiences of mothering, professional experiences, observations of their child which left them feeling uneasy, or just knowing because 'a mother knows'. One mother, Janice, explained her experience of this feeling as follows: *'I knew ... you know when there is something not right with your child, nobody else in my family believed me, nobody ...'*

This *'knowing'* was reported by some mothers as something they had voiced to their partner or medical professionals. Various, the women recalled being told that they were being overly anxious, or they were simply mistaken, or that the issue was not autism. Consistent with prior research conducted with Irish parents around diagnosis in this context, many mothers in the present study recounted how their worries fell on deaf ears (Finnegan et al., 2014), particularly with professionals such as their general practitioner. Despite their feelings being dismissed by their partners and extended family members, or reassurances that something else would account for their child's behaviour, mothers explained how they held fast to what they felt. As Kate recalls:

*'I went to the public health nurse and I was told, 'No, no, don't be silly'. She was actually very patronising. She said, 'Oh mammy don't be silly. He's a boy and they go backwards and forwards'. But I knew myself.'*

In their qualitative study of parents and diagnosis, Ryan & Salisbury (2012) similarly reported a 'boys will be boys' attitude from health visitors in response to mother's concerns about atypical behaviours of their children, sons in particular. Beliefs about gender related to diagnosing autistic children make assumptions that see autistic boys delayed in diagnosis because *'you know what boys are like'* (Ryan & Salisbury, 2012: 381) and girls misdiagnosed or missed completely, because autism can present differently in females making it more difficult to diagnose (Attwood et al., 2006; Kopp et al., 2010). Reflective of this, in the current study, the participant parents who reported waiting longest for a confirmed diagnosis - a total of seven years - were parents to an autistic daughter who, they recalled, was misdiagnosed twice before finally being diagnosed as autistic at ten years old.

The notion that diagnosis was no surprise was not the experience of all mothers in the study. Denise spoke of her son, John, who had experienced *'dystonia and muscle problems'* in the days after his birth and was put under the care of a paediatrician. She recalled the diagnosis of autism as a *'surprise'* because the focus had been on John's physical issues, but she said that diagnosis was less of a *'shock'* as the family had been dealing with paediatric specialists since John's birth. She added that she took some time to come to terms with the diagnosis. On her return to work after maternity leave, colleagues enquired about how her new baby son was doing. When they asked, *'Is he walking? Is he talking?'* she recalled answering *'yes he is'* just to avoid having what she called *'the conversation'* with them.

Another mother, Nuala, became emotional as she recalled being alone when she received confirmation of her child's autism and how that felt for her. She recollected:

*'It was strange really because I didn't know that's why I was going. I thought it was just another appointment. Niall couldn't make it so I was on my own. I didn't realise the severity of it ... I thought it was just another kind of meeting. Half way through I realised what she was actually saying and the severity of it and then I was gutted that I was on my own and Niall wasn't there'.*

Despite existing guidelines (Harnett, 2007), Nuala stated that was unaware that she might receive diagnosis when meeting with professionals on the particular day she describes above. She said she had been given the news along with a written report and remembered the rising panic she felt. Nuala particularly remembered her distress of having to go home alone to her TD children, and later relay this news to her partner, who himself had an adult autistic sibling. The report given to Nuala was overwhelming: *'It was massive, I remember thinking - we're never going to get through reading all this stuff.'* Ultimately, Nuala said that her shock dissipated and she resigned herself to this change in her family's situation stating: *'It is what it is'.*

Upon diagnosis, the emotion recalled by many mothers was primarily relief that their feelings had finally been vindicated, along with irritation with professionals who has not taken their concerns seriously, as Sue explains in the next quote:

*'So basically it was like - 'I told you so', you know? I said that in my head like ... 'I told you', and I was directing that I suppose towards Derek and grandparents and all the public health nurses, and the ENT and the GP'.*

Several mothers coped by framing the diagnosis as a positive. Mother participants used words and phrases such as *'relief'*, *'I knew'*, *'emotional relief'*, *'surreal but huge relief'*, *'sigh of relief'*, to describe their experience - frequently followed by their belief that, as Liz phrased it, *'I know what the issue is and now I have something to focus on, and I can work on it'*. This coping response is underpinned by the concept of cognitive reappraisal (Lazarus & Folkman, 1984). Lazarus & Folkman (1984) argue that paradoxically, cognitive reappraisal can be an emotion focused mechanism that involves reassessing a situation in a cognitive manner that allows an individual to reduce the emotional impact of a disclosure and by extension, the associated stress. In the short term, this can be an effective coping mechanism, especially if the source of stress is outside of the control of the individual. This method of coping was reported by several mothers as a strategy used

to manage diagnosis. Participant Nuala's earlier statement of *'It is what it is'* was likely underpinned by this strategy.

However, there were mothers who also recalled that being vindicated did not necessarily make diagnosis any easier to hear or to come to terms with. Lazarus and Folkman (1984) assert that emotion-focused coping does not provide a long-term resolution, and may in the end be counter-productive, as it delays practical and sustainable stress management.

Helen's reported experience had echoes of this when she spoke of the time it took her to fully realise the implications of her child's diagnosis, as the statement that follows illustrates:

*'...we went to Professor Murphy - the first diagnosis ... I knew myself for certainly the last 6 months ... I was expecting it definitely, and it was only later on when I got the second diagnosis that I was like - ok, right ... when I started to figure out that he's going to have to go into a unit, that's when things really became real for me. And the panic would have set in'*

Similarly, the issue of a delayed reaction was implied by Gloria's reported experience also. Gloria said that she had had worked with autistic adults, and her professional and practical approach to autism became her refuge in the immediate aftermath of her child's diagnosis. She recalled furious, driven activity, and endless planning that allowed her a sense of agency in the situation. Then later, several years along, she reflected:

*'No-one wanted to say it (professionals) and everyone was asking me what I thought it was. So no-one would actually say what it was. I thought I was going a bit mad for a while. It was a bit of a relief ... and then I threw myself into fundraising for him ... doing all the courses I could do ... it's been nearly three years since his diagnosis, its only now that I'm starting to worry about the future I suppose ... now it's another worry'*

Another mother, Fiona, spoke with searing honesty of her reaction to diagnosis – she did not recall relief or panic or vindication, but overwhelming sadness and pain. She recalled isolating herself from friends and family feeling unable to share her distress with anyone, including her TD children. She explains here:

*'When I got the diagnosis I can tell you, I wished cancer on him more than this and I know that sounds really dramatic, actually ... I couldn't say it to anyone ... I remember texting my sister and saying don't text me. Don't ring me. Don't come near me and she said 'it's not like cancer' and I said 'oh my God wouldn't that be so much better because he could get better from that'*



While all participant mothers expressed an array of feelings associated with diagnosis, without exception they reflected in interview that having a firm diagnosis allowed them to begin to process their grief and look to future planning in relation to supports for their autistic child. They reported feeling that diagnosis answered questions and also provided a cogent explanation for their child's behaviours that they could share with family and friends; however, TD children were not immediately included in this group. As Gray (2003) found, the experience of coping with diagnosis was different for fathers participating in this study in several respects, as the next section illustrates.

### ***Diagnosis – Experiences of Fathers***

In relation to fathers' experiences of diagnosis, culturally generated notions of, 'protection' and 'strength' that inform widely held beliefs about masculinity were evident in the data. The intuitive realm seemed to remain exclusively with mothers and was reported only by them. In many participant fathers' accounts, fathers positioned themselves as the 'strong' one or the 'fighter' for the family - the provider of economical and emotional support. This framing of the father role appeared repeatedly in fathers' recollections.

Participating fathers' narratives echo literature that finds that fathers coping with stress can sometimes take refuge in traditionally defined roles. Genesoni & Tallandini (2009) assert that this can happen for men through a father taking control (2009: 313). Moreover, Gray (2003: 634) argues that fathers often respond by suppressing or avoiding emotions associated with vulnerability by insisting that their child's diagnosis *'did not have a significant effect on them personally'* and this in particular was evident in what fathers in the current study had to say about their experiences.

With one exception, seven of the eight participant fathers exhibited an unyielding stoicism when recalling diagnosis. Fathers spoke of *'challenging'*, *'fighting'*, *'structure'*, *'planning'* and *'routine'*, when reporting their responses to diagnosis and their concerns about the future of the family. The idea of father as advocate, 'doing battle' for their child and family is one that appears in the literature and is anchored in problem focused coping that allows fathers to take practical action to ameliorate stress for the family (Lazarus & Folkman, 1984). Problem focused coping is characterized by problem solving, time management, and obtaining social support.

Burrell et al. (2017: 1141) describes fathers who place themselves in the role of 'advocate; seeking out and accessing as much support as possible from both public and third sector services'. This self-appointed role was evident in many participant father narratives. This can be seen in Larry's account of coping with diagnosis. Larry relayed the following heated exchange with a psychologist from the National Educational Psychological Service (NEPS) where he tried to anticipate, plan, and structure supports for his son shortly after diagnosis. Larry argued:

*'Like this NEPs woman says, 'Oh there's this new thing in - a monitoring way, where you can sign up and people help'. I said, 'For what?' She said, 'Oh you know when families are under pressure and stuff'. I said, 'We don't need that ... we're not going to hear nothing for ages'. This woman said, 'Oh you will, it's very quick. I said, 'It's not going to be quick ... how long will this take?' - 'Oh, you'll be on a waiting list'. And I said, how long roughly? I said, 'I don't want to go home and be watching a letterbox. How long? Is it a year? Is it two? ... So, what happens to him when he is eighteen? How many appointments do I get?*

Larry's frustration and distress were evident in interview as he poured out the above conversation, almost without pause. Larry's focus was on solutions. His attention to shock or grief was marked by its absence – he gave very little voice to this aspect of his experience. In a study of gender and coping, Gray (2003) notes that for men, managing diagnosis in this way is not unusual. Ostensibly, there was reluctance on the part of fathers in the present study to openly express distress, sadness or grief regarding their child's diagnosis and this can also be further seen in the following two accounts.

When asked to recount their memories, some fathers reported challenging the diagnosis or becoming angry. Derek explained his long held conviction that his child's difficulties were being caused by a hearing problem. He had argued this with his wife frequently and discounted her worries about ASD. He stated that his conviction that ASD was not the cause of his child's behaviour was strong and on the day of diagnosis he took convincing. Derek explained: *'I challenged the diagnosis on the day, just - I had questions that I wanted them to address'*.

Alternatively, responses included suppressing sadness in favour of anger. Larry reported that the meeting with the psychologist who disclosed his child's autism was uncomfortable - fraught with distress, and for Larry this distress was quickly replaced by anger and disbelief, as the next quote highlights:

*'I was thinking for that few seconds that I was going to start crying to be honest ... so... I said to him ... how do you know that when you've only sat with my son for like forty-five minutes? I was probably a bit angry with him ... a bit not really nice to him to be honest ... it was like I was calling him a liar as well*

*... he had obviously been in that position before because he just kept looking ... he said 'do you want me to finish this meeting and I'll talk to you tomorrow?'. I said 'no, just do it now'.*

Larry reasoned that the fact that the practitioner who disclosed diagnosis was not fazed by his aggressive response must mean that his reaction was one that the psychologist had seen from fathers frequently.

Another dimension to the issues of responses to diagnosis was the inverse of the above. Some father's accounts indicated feelings that they may not have been consciously aware of, but that were nonetheless expressed circuitously. As Gray (2003: 634) found in his study of gender and coping, fathers often *'believed that the most serious impact that their child's autism had on them was through the stress experienced by their wives'*. The current findings reiterate Gray (2003), in that, if vulnerable emotions were overtly expressed by participants, it often happened in the role of 'protector', framed by the father as a feeling for their partner more than a feeling originating within their own experience. This indirect feeling of emotions was among the few reported expressions of vulnerability or grief that fathers allowed themselves. Frank, another father who had dismissed his wife's concerns about ASD, did not articulate his emotions on hearing of the diagnosis but instead recalled only his wife's distress, *'I remember it yeah. Fiona was very upset'*.

For another father, Hugh, diagnosis was no consolation or vindication. As Wayment & Brookshire (2018: 1155) found in research with mothers of autistic children, because the aetiology of autism remains unknown, parents can often, *'come up with their own beliefs about the origins of their child's diagnosis'*. This can lead a parent to feel responsible or think they have somehow caused their child's autism, as participant father Hugh's statement below illustrates:

*'I still feel that - and I suppose since he was diagnosed, I'm wondering - I think it's from me. I think he inherits some of the traits from me ... just with a thought on what I was like as a child ...I always felt stupid ... and I don't want him to feel like that'.*

Beliefs about what it is to be a good father, encapsulated in the notion of fighting fathers (Burrell et al., 2017) worked against Hugh, who further stated, *'I'm the father in the house'*. As such, he held himself accountable for not being able to remedy the situation the

family found themselves in, adding , *'Its not what I had envisaged for myself ... and I suppose I just despair why can't I control this ...'* .

The language of fathers around diagnosis was largely devoid of vulnerable expressions of emotion, with the news described as *'stressful'* or something they *'had to accept'* being typical responses to questions around their feelings about it (Gray, 2003). Participant fathers' accounts saw them most comfortable in discussing the practical requirements of diagnosis rather than its emotional effects.

In the main, narratives indicated that both mothers and fathers saw diagnosis as a step towards a resolution of sorts. Parents stated that diagnosis gave answers to some questions that had been unanswered for an extended period of time. They added that diagnosis furnished them with a vocabulary that allowed them to articulate for the family and extended family members, exactly what was happening for their autistic child but struggled in the immediate aftermath of diagnosis to have the same conversation with their TD children. They felt that diagnosis, now confirmed, would allow them begin to plan for changes to family functioning that would be required.

Despite the uncertainty that can lie at the core of a diagnosis of autism, parents felt as previous research with Irish parents has found, that diagnosis became the springboard from which future planning regarding school placements and support, could get underway (Finnegan et al., 2014). All parents asserted that they remained aware of the implications of diagnosis. At the same time, they managed this reality by nurturing the hope that interventions and support for their child would mitigate negative outcomes and facilitate positive development. Parents' accounts of their thoughts on the future were invariably tempered by this hope, as Liz explained:

*'You automatically think, you know ... what will he do in his future ...will he get married, will he have children and now we're a few years into the diagnosis and I know that, you know, school - he'll take it at his own pace, he'll get there – he'll get through it. If he wants to get married he can go ahead and get married (laughs) ... you feel like your world is closing in on you when you do get a diagnosis ... having said that, he might be on the spectrum but he is five also ... he can be a 5 year old as well you know so...'*

As many participating fathers had, Niall reasserted that his child's diagnosis did not intimidate him and went on to express hopes similar to Liz, as the following quote illustrates:

*'I don't feel threatened by his diagnosis, I can see that he's a bright kid... there's no doubt he has his issues but nothing like some ... so I kind of feel a bit odd, I don't like to label him because, not because I don't want him to be seen like these other kids but I don't think he deserves to be'*

### ***Diagnosis – Parent experiences of telling TD siblings***

Beliefs about childhood that construct children as innocent, *'uncorrupted by the world they have entered'* can determine our attitudes towards children and our expectations of them (James et al., 1998: 13). The belief that children were incapable of understanding, or alternatively insensible to 'adult' concerns, was evident in what parents recalled doing or not doing when they considered how they might broach diagnosis with the typically developing children in the family.

The diagnosis of ASD and its implications were reported by participant parents as being experienced primarily as a parental rather than a family issue. No participants expressed an awareness around neurodiversity and its arguments. No participant disclosed having diagnosis explained to them as anything other than a disability. Processing the diagnosis, and thoughts of how it might affect the family unit moving forward, was largely recalled by parents as initially happening without any reference to TD siblings in the family so they were inadvertently excluded at this very important juncture in the life of the family unit. The majority of parents remembered that immediate thoughts and plans for the future concerned only the child with ASD, as Liz explains in the following quote:

*'We don't put enough time into thinking how it does effect kids you know, we just think ... this is how its gonna be – and expect them to kind of just be on board with it and that's not the case, not the case at all...'*

Moreover, as the next quote illustrates, another parent, Hugh, revealed that it was only occurring to him in that moment while being interviewed, that he and his wife had never actually sat down and had a conversation with their typically developing children about their sibling's diagnosis of autism when they received it,

*'I can't remember where we purposely sat them down ... we are only thinking about it now because I'm talking to you and yourself and Helen made contact. But before it wasn't a consideration...'*

According to existing research which examines childhood in the context of chronic illness, children in this context, though subject to the rules and regulations of the home set down by the parent, can often find themselves excluded from the adult world of information and

decision making (Bluebond-Langner, 2000). This means that the TD children in the family are left living in the shadows cast by the disability while also struggling to understand what is happening.

In the current research, this became evident in various ways. In all families, typically developing participant children were confirmed as living in the family home. In talking about home, the majority of children described variants of a scene, namely; the distress of a parent who was *'sad and crying'*, the frustration or stress of a parent who was *'getting really annoyed'*, and the outbursts of their autistic sibling who was often, *'really mad about weird things'*. Additionally participant children remembered witnessing violent outbursts by their autistic sibling, directed at a parent or at the TD children themselves. Other TD children recalled hearing appointments being made by parents for equine therapy, speech therapists, or child psychologists. Reflecting Bluebond-Langner's (2000) assertions, most participant TD children were left confused, and recalled not fully understanding why this was happening in the family, primarily because they had been excluded from information that would allow them to do so.

Typically developing children's accounts saw them as a spectator to a huge sea change unfolding within the family and this observation is strongly supported by parents' accounts also. Many parents reported that, while coming to terms with diagnosis themselves, they struggled to explain what was happening in a clear and cogent dialogue with the TD children in the family. In speaking of learning about diagnosis and the autistic child, Finnegan et al. (2014: 78) highlight the parents' *'feeling of needing to protect their child'*. Parent narratives in the current study suggest that this impulse to protect can extend beyond the autistic child to TD children in the family also, although paradoxically, doing so had the potential to generate significant anxiety for the TD child.

Through parent reports, it emerged that, in the immediate aftermath of diagnosis, when TD children actually managed to ask questions prompted by what they were seeing and hearing in the home, sometimes they were not told the truth, copper-fastening their exclusion (Bluebond-Langner, 2000). For example, after the disclosure of diagnosis, one mother Fiona recalled that her distress was obvious to her TD child. She went on to say that she answered her TD child's questions by telling the child that his autistic sibling *'was getting his ears tested'*. In a similar scenario, in answer to her children's questions, another mother vaguely told her TD children that their sibling was *'just getting things checked'*. Some parents recounted their feeling that a conversation with their TD child about

diagnosis was something they could not deal with immediately after diagnosis. One parent, Larry, reported not responding to his child's questions at all because he was at a loss as to what to say as he recalls below:

*'She's asked me why he's always going to the doctors and no one else's brothers are going to the doctors ... I just haven't said nothing to her as such like that, because I don't really know what to say'.*

Alternatively, in other accounts, there were parents who explained their belief that the TD child lived in the house and so, by extension, must see, must know, must understand that autism was the cause of events unfolding in the home. One mother, Claire, was mystified at how her TD child would not *'pick up on it'* when the child had been, *'hearing this all his life'*. The assumption implied by these parent accounts was that the TD child, by osmosis, could or should be able to make sense of what they were witnessing. Immediately after diagnosis, information was not shared explicitly with TD children by either parent, as parents reported believing that given the very observable behaviours of their autistic child, something as obvious as autism did not need to be stated overtly. As previously discussed, cognitive sophistication in children's thinking about autism, measured by Glasberg (2000) found that daily exposure to their autistic siblings behaviours, together with their experiences at home, did not advance TD children's understanding of autism.

The current study, similarly found that, *'parents consistently over estimated their child's understanding'* of autism and its implications (Glasberg, 2000: 153). Parent narratives suggested that they failed to grasp that young children do not necessarily make links between what transpires in the family and their sibling's diagnosed condition of autism. One mother Denise explained that she eventually discussed autism using the more familiar term *'special needs'* with her seven-year-old daughter, Elena. Denise believed that Elena had a good understanding of what is meant by *'special needs'* simply because Elena accepted this explanation without question. Although Elena used the word autism in interview, it quickly became apparent that her understanding of autism was limited, as discussed later in this chapter.

Where disclosure of diagnosis and conversations with TD children eventually took place, parent accounts implied the unspoken belief that such conversations were the domain of 'mother'. This was evident in that parents reported that the mother in the family was the go to person if the TD child had a question about their autistic sibling or diagnosis – as Frank explained, *'He'd ask his mam more so than me'*. Parent narratives revealed that the

mother's responsibility in explaining diagnosis dominated ongoing discussions that emerged with typically developing children in the family. This reflects what Gray (2003) previously found, namely, the emotional dimensions of diagnosis are managed mainly by mothers. One father, Hugh, said of ultimately telling the TD children: *'Helen did have a chat with them and probably told them more... and showed them a video'*.

There were exceptions however to how TD children found out about their sibling's diagnosis. Participant mother, Fiona, remembered her own coming to terms with the diagnosis was difficult – so much so that she recalled, *'I couldn't say it to anyone'*. She went on to add that this included her TD child. Her inability to discuss diagnosis with her TD child continued for a period of time, even after it was commonly known in the community in which the family lived. Speaking of her TD child, Fionn, she continued:

*'He was told by another child and it was very negative ... he didn't want to tell me what the other young lads said to him in the yard because he said he didn't want to hurt me'*.

Fiona went on to add that, *'I don't think Fionn will ever really tell me what he really, really feels because he was very protective over me'*. Fiona's was not the only family where the impulse on the part of the TD child to protect the parent around issues of diagnosis became evident. As previous research in this context has found, narratives from both parent and child participants in this study clearly showed TD children engaging in *'precocious'* caretaking behaviours (Benderix & Sivberg, 2007), which saw TD children taking up the role of emotional caregiver to the parent, as Fionn above did. Data showed this occurring most frequently among participant children where information from parents was scant or totally absent. Barnett & Parker (1998) argue that the child's impulse to be caretaker can develop out of a desire to remain closely connected to the parent and to avoid feelings of anxiety or loss, an argument which, is tenable in this context.

Such was the reported anxiety around diagnosis for some parents, that in one family - where TD children were told of diagnosis - the parents said they had decided not tell the autistic child that he was diagnosed with autism; again reiterating what Bluebond-Langer (2000) found in her research with families. It was only on the advice of their 10-year-old daughter, Milly, who argued *'I think it wouldn't be nice on Micah if he heard from somebody else'*, that the parents eventually did disclose diagnosis to the diagnosed child.



All of the participant families were two parent families when they received the diagnosis of autism. Subsequently it was reported by mothers that two of the parent relationships had broken down – partly due to the pressures generated by the needs of the autistic child. In both cases reported in the present study, mothers stated the desire of the fathers to maintain relationships with their TD children through regular visitation, but in each case, it was reported that neither father wished to maintain the relationship with their autistic child. One participant child reported being aware of this rejection of her autistic sibling because of diagnosis. The child, Eavan (10), stated that she visited with her father alone because *'Elizabeth doesn't see him anymore ... because he's kind of mean to her'*. When Gloria, one of the mother participants, asked her former partner why he did not want to take his autistic son for visits, she recalled that her partner had told her, *'Ah, I just can't handle him'*. Gloria recalled too that this rejection of her sibling was something that her young TD daughter heard and was aware of. Differentiation that sees one child rejected by the parent, if seen by the TD children as unjustified, can leave the TD child feeling vulnerable to similar treatment (Kowal & Kramer, 1997).

Ultimately, parent narratives clearly exposed the dilemmas they felt regarding what they should tell their TD children about diagnosis, an issue deemed by many parents to be largely an 'adult' concern. As discussed, there were those parents who did not know what to say about diagnosis to their TD child and so they said nothing. Several eventually told their TD children about diagnosis and explained what autism was, only to never speak of it again. Some reported that they felt their TD children had been too young to be told at the time of diagnosis and of those parents, and of these several recalled they did not think to broach the subject again when the TD child was older. A number of parents remembered eventually dealing with diagnosis in a planned manner using ASD resources such as books and videos, and recalled the dialogue with TD children evolving as time passed.

As previously mentioned here, there were those parents who reported that although the logistical and emotional family issues that grew out of the ASD diagnosis were often discussed when the TD child was present, no direct discussion took place with the TD child about autism and its effects. These parents stated their belief that the children saw what was happening and therefore knew about their sibling's diagnosis. This approach to TD children in the family prevailed even though parents did not always have the same expectations regarding an understanding of autism from other adults who might observe

the ASD child's behaviours, be it distal family members or a stranger in a restaurant for example.

Parent accounts about the 'invisibility' of ASD is mentioned in existing literature (Moyson & Roeyers, 2011; Nealy et al., 2012; Woodgate et al., 2008). In the current study, several parents similarly spoke of the invisibility of their child's condition and it seemed to register with them primarily in relation to those outside of the home but not the TD children in the home. Parent reports showed they were more aware of strangers' reactions to their ASD child and were more inclined to offer an explanation in those circumstances. In discussing diagnosis and attitudes to autism inside and outside of the family, one mother Liz stated

*'Even publicly, I find myself saying to people ... 'he's having a bit of a melt down' ... and stuff like that so I'll always educate people - I'll always let them know he's not bold ... having said that ... I never actually kinda explained to her (TD child) what autism is ... you kind of generally feel that the kids - that they kind of pick up on it and that she has to have a bit of an understanding, but I've never actually sat down and explained it to her'.*

Participant parents beliefs about their children's ability to engage with diagnosis raises questions debated by researchers about children as human 'beings' or human 'becomings'. Uprichard (2008) argues that a 'becoming' discourse of the child that conceptualises the child only as an adult in the making, diminishes the child's immediate everyday reality of being a child – it is future orientated and it is how children have traditionally been understood. A 'being' discourse sees the child as a social actor, actively constructing childhood. Uprichard asserts that children are both '*always and necessarily being and becoming*' (2008: 303) and viewing them as such increases a child's sense of agency as it takes account of who the child is now, in addition to the adult in the making. The 'becoming' discourse of children sees the child as lacking now but moving towards adult competency. It does not acknowledge that both adults and children are competent and incompetent in various domains throughout a lifespan.

A construct of children as 'human becomings', when applied to participant parent reports in the present study, may explain why often parents said that a conversation about diagnosis with their TD children was something for the future. However, Milly's reported observation and advice to her parents, regarding her sibling, suggests a wisdom we assume to be held exclusively by adults - and illustrates that young children, despite their as yet limited life experience, are competent enough to make valuable contributions to the family

in managing diagnosis. Milly's mother, Marie, acknowledged this, observing, *'Her opinions matter, she can see things that I don't see'*.

Parents frequently asserted their belief that the child diagnosed with autism *'needs me more'*. The ways in which a child adjusts to diagnosis and its implications, and the degree to which a TD sibling is affected has been found to be dependent on family relationships (McHale et al., 1984) – and arguably the parent child relationship is a pivotal factor. Participant children's narratives demonstrate that in the light of diagnosis the typically developing children need their parents just as much, but perhaps in a different way, as the next section illustrates.

### ***Diagnosis – Experiences of TD siblings***

Much extant research that explores how children develop understanding in relation to lifelong, chronic conditions such as autism, follows the developmental stage concepts of Piaget's model (Bibace & Walsh, 1980; Glasberg, 2000; Ferraioli & Harris, 2009). Children, in the preoperational stage of development, that is children up to age seven years, understand the world according to their immediate experiences (Piaget et al., 2011). For these children, discernible autistic behaviours constitute their understanding of autism. Research also finds that older children tend to have a generally good understanding of autism (Glasberg, 2000; Ross & Cuskelly, 2006) In this study, such findings held true with the youngest participants and to a limited extent in the case of the older children aged 10-12 years old.

In the current study, there were participant children who reported having a clear memory of being told about their sibling's autism and there were others who did not – these children recalled that they *'just knew'*. Some parents reported having revisited conversations about diagnosis with TD children in the light of their upcoming interview for the present study. Rubovits and Siegal (1994) find that a naïve understanding of their sibling's condition may be protective for younger children in that they cannot conceive of the full implications for the family. As a result, they perceive their siblings diagnosis as less concerning. The children's accounts of diagnosis in this study reflected this given they were largely lacking the strong emotional component that had characterized many parent accounts, particularly younger children's accounts. They seemed to process the news in a very straightforward manner, with one eight year-old child, Joe, stating: *'It's not their fault that they get autism'*.

The ways in which an understanding of autism was reported among participant children varied. With the exception of one 6-year-old participant, all of the other 14 children had eventually been told by their parents that their sibling had a diagnosis of ASD. When asked what they understood that to be, younger children made statements like *'he makes funny noises; or 'he pees on the floor'; or 'he gets a tantrum'*. In interview, 6-year-old Gina's response to questions about her brother's autism and what autism is, was quite typical of younger participants, *'he goes, 'woow...ohhhh' because that's kind of a bit of a funny voice ...'*. This would reflect Piaget's observations of the preoperational stage of cognitive development (Piaget et al., 2011). Younger children accounts showed that while they could name the condition 'autism' they understood autism exclusively through the lens of observed behaviour without reference to what might cause that behaviour. Elena, one of the youngest participants, said immediately in interview, *'I have a brother with autism'*. Although she could name the condition, the limits of her understanding of it became apparent as she continued, and later, speaking of her brother, John, she added:

*'I just don't like him ... I don't like cause he can't play ... then I've no one to play with ...we go on the swings ... he doesn't like them ... He's scared of them ... Even though he's nine he's still scared of them ... its not fair cause he won't play with me'*  
[Elena 7]

Elena did not attribute John's disinterest in play or his disinterest in her to his condition. Her assertion that *'he won't'* play suggested her beliefs about her brother's agency in his condition and demonstrated the bounds of her understanding, compounded by a lack of information. However, the loss of her playmate was felt keenly because she added that *'lonely'* was a word she would use to describe how she feels about this.

All children referenced the fact that life had changed since diagnosis and that this could be stressful. Twelve year-old, Christopher, articulated this best when he said: *'Before you'd do something and it wouldn't be **you** causing trouble ... when you do something now it is you causing trouble I'd say'*. Other children had framed diagnosis more positively as kind of *'fun'* or a *'superpower'*. Hope, aged eight, acknowledged that life at home had changed and said that although it could feel stressful having an autistic brother, *'Sometimes ... most of the time, it's really fun to have Henry around'*. Child participant, Joe, was similarly ambivalent. He spoke affectionately of his sister while at the same time bemoaning the loss of his playmate stating: *'I'd say it's brain damage and they do different stuff in their minds ... there's nothing different, they only need a little bit more care than other people ... It's ok, but sometimes I do wish there was someone to play with'*.

Older participant children's overt explanations appeared to suggest a level of understanding that was a little more sophisticated. These children made statements such as, *'They're kind of living inside their own world – in their little head'* [Amy 12] or *'It makes it difficult to socialise and learn'* [Christopher 12]. However, regardless of their ability to articulate a more complex explanation of ASD, older children's narratives indicated that their understanding of its implications remained somewhat limited, as Glasberg (2000) has found.

Moyson & Royers (2012) explored the notion of the 'invisibility' of ASD, particularly in relation to the experiences of siblings. They found that, because children with ASD exhibited many positive as well as problematic behaviours, there was room for siblings to believe that the child with the disability could control their autism. Given that their sibling's condition was not always discernible, a belief that prevailed among some of the TD children in the current study was that ASD was somehow intermittent and operating at the whim of the autistic child. Some accounts in the current study also implied TD children's beliefs that their ASD sibling was capitalizing on their diagnosis. Children reported how their ASD sibling might be *'allowed on her computer'* or *'play board games'* yet *'gets no Irish homework'* or *'doesn't have to do tests'*. Such beliefs demonstrated the parameters of their understanding exacerbated perhaps by a lack of information from parents intended to protect them. The strain that these beliefs might bring to bear on the relationship between the typically developing child and their parents also became apparent in accounts.

A limited understanding of the diagnosis evident in children's accounts saw some complain that their ASD sibling did not have to help with chores because they *'sit on the sofa and watch TV'*. Others referenced feelings of resentment towards parents about having to *'fend for'* themselves because *'they help him with loads ... but they don't with me'*. One 12-year-old TD sibling, Christopher, summed it up by saying;

*'She could hurt herself ... they're always on alert for those things - like the same as you would for a small child basically ... then it's like for me it's fend for yourself ... she doesn't get consequences ... but I was being consequenced (sic) since I was 5 years old!!'*

Christopher's insight that his sister needed parenting as a small child would, did not mitigate his sense of injustice that he did not have the allowances made for his behaviour that his sister did for hers. His account showed that his understanding of diagnosis did not extend to the realization that consequences for his autistic sister could never be on par with the consequences he might expect for himself. Research shows that differential parenting of this kind inadvertently carries implicit messages about what typically developing children in the family are allowed to need and expect for themselves from their parents, which may by extension have implications for developmental outcomes for TD children (Boyle et al., 2004). However, it should be noted that research has also found that differential treatment by parents, when experienced by TD children as justifiable, because it is connected to the disability of a sibling, poses less negative effects for the TD child (Kowal & Kramer, 1997).

Angell et al. (2012) found that TD children, while accepting of their autistic siblings behaviours in the home, experience embarrassment when those same behaviours take place in public. In the current study, older children similarly expressed embarrassment about diagnosis, especially if their sibling engaged in ASD behaviours in social situations like a school club, a restaurant, or church. In those situations, parents reported how TD children looked to them to somehow control the behaviours of the ASD child. Participant mother Marie reported the following exchange at church with her 10-year-old TD child:

*'He (ASD child) was getting rid of his energy climbing over seats ... she then said to me, mum can you get him to stop that? And I said, why what's wrong ... she goes, mammy he looks like a monkey... I thought she was joking. So, I said ...he's just climbing over certain things. And she said, mammy ... it's making me very embarrassed ...'*

Incidences like these indicate that, despite statements from older children that suggested a seemingly sophisticated understanding of diagnosis, in practice the TD children's narratives showed that they believed that the parent and /or the autistic sibling had some agency over behaviour and it could be 'fixed' when necessary. While older children could communicate their understanding that autism likely originated in the brain, and they could name the challenges regarding socializing and learning that their autistic siblings might encounter as a result, their assessment of the implications of the condition were not fully understood.

When asked about their beliefs regarding what their TD children understood about autism, several parents reported that their child's understanding was limited and it was a topic that

would need to be revisited frequently. They said they saw living with diagnosis as a family journey where they would learn together. Alternatively, there were parents who explained what they had told the TD children about autism– and their belief was that the children understood diagnosis and its implications, simply because diagnosis had been discussed. Some parent beliefs were irreconcilable with what the participant children related in interview. One parent, Emer, said of her 10-year-old, Eavan, that she had:

*'A very good concept of ... autism affects, you know, communication and socialization ... Eavan gets it. I suppose she has lived with that ... but she is clever. So, you know, she picks up on things. She understands. She has lived with it all her life and I have always had a policy of being very open with that, with everything in general but this specifically.'*

In interview with Eavan however, the following exchange took place,

R: Do you know what autism is?

*Yeah it's like...its special needs but it's like a lot of different stuff.*

R: Can you think of one?

*No.*

Participant parents' over estimation of their child's understanding of diagnosis, reported in interview, resulted in mismatches such as this in the data, and they were not uncommon (Glasberg, 2000). Some parents asserted that children could 'see' and therefore 'knew' and 'understood' what was happening in the home and were resilient in the face of it, especially parents of older children. However, it is worth noting that this might be explained given that Glasberg (2000) states that concepts related to an emotionally laden topic may take longer for children to acquire. This may clarify why a 10 year old TD sibling like Eavan struggled to some extent to explain her sibling's condition or why 12-year old Christopher is 'mortified' by his sister's behaviour.

In addition to understanding, when parents were asked about what they think their TD child feels about their sibling's diagnosis, some statements were striking. Participant father, Rob, said of his 12 year-old TD daughter, Amy, 'I don't think she thinks too deeply about it'. There was evidence however that older children did sometimes think deeply about autism or worry that they may be autistic themselves. Amy expressed resentment that her parents are 'more focused on him (ASD child) and ... I just kinda ... I just have to stay out of the way'. In addition, Ciarán, father to 12 year-old Christopher, shared of his

son: *'He has asked a couple of times if he is autistic as well, or is it something we are not telling him. Is there something that we are not telling him to do with ASD'*. This again suggests that a lack of information was a source of anxiety for TD siblings who, in the absence of such information could come to their own erroneous conclusions.

Similarly, when asked about his perceptions of his TD child related to diagnosis, another father, Niall, said of his six year old daughter, Nell, *'I don't think worries about anything, other than unicorns! And where the next McDonalds is coming from?'* However, when discussing worries in interview, the following conversation took place with Nell,

*N. I feel sad.*

**R:** You feel sad? ... When?

*N. Every day.*

**R:** Every day? (Child nods) Can you tell me why you feel sad?.

*N. I don't know ... I'm worried if a person does make me feel sad.*

Nell's conflation of sadness with worry indicated she had some feeling that she could not quite articulate, but the feelings were there nonetheless. Beliefs like those expressed by both Rob and Niall may be generated by culturally informed narratives around children that construct them as alternately, knowing but resilient, or innocently oblivious to what is transpiring within the family (James et al., 1998). Narratives in this study suggested that such beliefs have the potential to cause a parent to underestimate what might be happening in the interior emotional lives of young TD siblings.

## **Conclusion**

This chapter focused on children, mother, and fathers' reported experiences of diagnosis of ASD for a child in their family. Participant accounts were diverse and exposed the emotional and often daunting task for families in securing a diagnosis and subsequently accepting and processing the changes to the family unit as a result.

Parents responses demonstrated the emotional upheaval associated with receiving and coming to terms with a diagnosis. As the parent, they must consider not just the autistic



child but also all other children in the family, as life adjusts to accommodate their changing situation. Parents' desire to protect their TD children – and the difficulties that can arise from this were evident in accounts. By excluding TD children from information about their sibling's condition in efforts to protect them, parents could unwittingly exacerbate the TD child's anxiety. The need for diagnosis and its implications to be discussed and revisited regularly was clear.

It also became apparent that the parents' approach to disclosing diagnosis to the TD child and subsequent discussions (or lack of discussion) of it was pivotal in the 'story' that the TD children told themselves about their sibling's condition and by default their experience of it. Typically developing children's uncertainty and occasional resentment connected to diagnosis was apparent in their accounts. That children are not bystanders but rather core players in the dynamics of the home was evident in what they had to say about diagnosis and the changes to their lives as a result. This is discussed in more detail in Chapter Six.

What became apparent in discussions of diagnosis was that, devoid of the notion of neurodiversity (as discussed in chapter 1), a diagnosis of autism for a child was understood by families as a problem, a deficit rather than a difference. In interactions with professionals such as paediatric consultants, no parent reported that diagnosis was disclosed as anything other than a problem – bad news if you will. This presentation of diagnosis by clinicians trickled down into how parents understood and experienced diagnosis and how they in turn presented the news of their sibling's diagnosis to other children in the family.

The recollections of both parents and TD children showed diagnosis as a life-changing event. The tension between fear and acceptance, the known and the unknown, coping and hoping, was evident in what families had to say. To use the phrasing of one mother, this *'forever change'* in the context of the family's life is the subject of the next two chapters that looks at how this change manifests in the family home on any given ordinary day and how this, in turn, is experienced by TD siblings in the family.

## CHAPTER FIVE

### FAMILY LIFE IN THE CONTEXT OF ASD

#### THE ‘PUSH AND PULL’ OF PARENTING AMPLIFIED

##### Introduction

Chapter Four focused on diagnosis - pre-diagnosis concerns, the ultimate disclosure of a diagnosis of ASD and how this was understood and experienced by all family members. This chapter explores living with a child diagnosed with autism and the resulting changes to the family unit because of this. The original intention was to report on children’s accounts first, followed by parent accounts. Having carried out field work however, what became apparent was just how young the child participants were – the youngest two participants were just six years old. To begin an exploration of findings with the children’s narratives alone risked reporting without context and would have required a lot of explanation to provide the context. These explanations had the potential to perhaps drown out the children’s voices. Therefore a decision was made to explore adult narratives first, thereby providing a context for understanding what follows. This approach is not intended to prioritise parent accounts but rather to bolster and support child accounts of lived experience.

Findings that follow examine accounts of daily family life reported from parents’ perspectives by considering the emotional climate in the family home, parenting in this context, the attending implications for the parent-TD child relationship and the home life of the family unit. Parent accounts related to their TD children are presented first to contextualize accounts from TD children that follow in Chapter 6.

The second theme, ‘The Push and Pull of Parenting Amplified’, is the subject of this chapter. This theme is derived from accounts which clearly demonstrated the experience of parenting - and the joys and challenges inherent in it – are heightened in significant ways when parenting takes place in the context of ASD. Aware that their context is unique, participant parents reported that they aspired to be attuned, responsive parents while

simultaneously being plagued by doubts about their efficacy, particularly in relationship to their TD child. This chapter explores the emotional climate in the family home, parenting, parental mental health, and social support, and examines how they manifest in the parent-child relationship in this context.

As noted earlier, the emotional climate of the family home, the psychological functioning of parents, and the parent-child relationship, though mediated by the broader social context and genetics, largely determine a child's social emotional development, as it is within the relational framework of family that children primarily learn to manage relationships (Belsky, 1984; Eisenberg et al., 2006; O'Connor & Scott, 2007). When examining the links between parenting and outcomes for children, O'Connor & Scott (2007: 6) assert that, '*children's real-life experiences and exposures directly or indirectly shape behaviour*'. Accounts in the Chapter Four suggest that a diagnosis of autism may trigger an emotional rollercoaster of change for a family that can initially seem overwhelming, creating as it does real life experiences and changes for all family members that are unique to this context. The singular profile of deficits associated with the autistic spectrum is key in this. These experiences, by extension, can then inform the how TD siblings are parented.

Accounts in existing research literature illustrate that following diagnosis, parents and siblings must come to terms with the equivocal nature of the diagnosis, its aetiology unknown, and its prognosis ambiguous. Emotional and practical adjustments to family life, including, renegotiating parent-TD child relationships, managing the environment of the home, and the re-organisation of family roles, are inevitable if the family is to accommodate stress and develop functional mechanisms and strategies for coping with changes (Burke, 2008; Bayat, 2007). Bayat (2007: 711), using a strength-based model, found that families raising an autistic child, who manage to successfully negotiate such adjustments, grow from adversities, '*despite extraordinary challenges faced by families of children with autism*'.

In the current study, the mean age of the autistic child was relatively young, 6.6 years old. The mean age of the typically developing child was 9 years old. Most parents considered that they were in the '*early days*' of learning to adjust to life with their autistic child. They optimistically expressed the hope that the, '*extraordinary challenges*' (Bayat, 2007: 711) they face now would become more manageable as they strived to be the best parents possible as their children grew older. They added their belief that, through experience, they would become more adept at parenting in this context. King et al. (2009: 60) argue that this

kind of *'striving'*, which *'future oriented'* is protective for families in this context as it is linked to resilience.

According to Wayment & Brookshire (2018: 1154), in a home where a child has a diagnosis of ASD, mothers are most often the primary caregivers, and this was reflected in the fact that of 20 participant parents in this study, 11 of 12 mothers were the primary caretaker in the home. Research finds that mothers tend to be more available to participate in research than fathers (Bailey and Powell, 2005). Thus, in the current study, parent accounts of the emotional climate and parenting the TD child on an average day, came largely from mothers – while fathers contributed their experiences of evenings, weekends at home and holidays also.

Relative to the body of studies that examine family issues related to autism, a meta review of the literature indicates that little is known concerning the quality of the parent and TD child relationship in the context of ASD (Hastings, 2014). In the present study, which examines how parents and children experience this relationship, participant parents identified three key concerns that they experience related to parenting their TD child in this context. These were referenced repeatedly in various ways by all parents, namely: participants' worries that they were failing as parents to their TD children due to stress in the home generated by their context; parents' feelings of powerlessness to manage this consistently and effectively; parents' anxiety about their typically developing child's quality of childhood - and linked to this, their concern that their TD child was *'growing up'* too quickly because of the issues they were exposed to within the family, connected to the autistic child's disability. The ways in which such concerns are generated is explored in the next section, which looks at the emotional climate in the home.

### **The Emotional Climate of the Family Home**

Bronfenbrenner (1986) asserts that the home and family is one of the primary contexts in young children's lives. Research finds that having a disabled sibling may *'alter one primary context of children's lives, their family environment, in fundamental ways'* (McHale et al., 1984: 421) In the current study, participants were invited to share their experiences of the family environment and the emotional climate of the home by speaking about both good days and 'tricky' days– the more neutral term 'tricky' being used to allow

participants infer from that as they might. Notably, 34 of the 35 adult and child participants in this study reported that the key determinant when it came to the emotional climate and parenting in the home on any given day was the ASD child's behaviour. As previously discussed in Chapters One and Two, challenging behaviours are the autistic child's way of communicating their distress in times of sensory overload, or upset when their routine is interrupted. One mother in the current study managed the children each day at home alone and three evenings per week alone as her husband was engaged in further education, Helen, explained such behaviour as follows:

*'Henry gets very frustrated, and I can't get him to cooperate with anything. So I end up getting in a panic ... The tension and bad days would revolve around Henry's meltdowns.'*

Children too communicated that their experiences of 'good days' or 'tricky days' at home was determined by their siblings meltdowns and the effect it had on them. Many of the children adopted an exasperated tone when speaking about their sibling's meltdowns, as the following quotes from child participants illustrate:

*'A couple of months ago he had - he had a meltdown that lasted for about 4 hours! Just a complete melt down ... he kept screaming and I couldn't go to sleep' [Amy 12]*

*'Sometimes she can be crazy ...she used to never go to sleep and kept on going out of the bed and all and I'd have to go into my mams room, so that I'd get some sleep for school' [Joe 8]*

*'Kim could be throwing a tantrum or throwing toys ... she kicks doors, she nearly broke the back door ... she never hit me, but she hit my mam and bit someone [Kyle 10]*

All participant parents reported that they were aware of the disruption to the lives of their TD children as described by participant children here, and noted elsewhere (Moysen & Roeyers, 2012; Petalas et al., 2009). The disruption and stress was reported by parents, as being generated by the behaviours of the autistic child. Moreover, all acknowledged that this had the potential to be detrimental to their TD children. One mother, Kate, a teacher who had two autistic children, said she tries to address this openly with her TD child, saying:

*'I often say to him, you know, we are sorry. We didn't expect this for you and this is not the childhood we wanted. But, you know, this is what we have been given'.*

The challenging behaviours of autistic children are manifold and are well documented (Ferraioli & Harris, 2009; Griffith et al., 2010; Johnson & Rodriguez, 2013; O'Moore, 1978; Rodgers et al., 2012; Woodgate et al., 2008). A systematic review of the literature that comprehensively documents the kinds of behaviours that ASD children can exhibit when stressed was carried out by Johnson and Rodriguez (2013). Johnson and Rodriguez (2013) delineate autistic behaviours as belonging to four broad categories: sensory defensiveness, hyperactivity, non-compliance, and self-injury. All of the categories outlined by Johnson and Rodriguez (2013) were evident in parent accounts of autistic behaviours in the current study.

Participant parents in this study shared their belief that, because of their ASD child's behaviours, their experience of parenting was qualitatively different to the experience of other parents that they knew, such as extended family members and friends – some of whom had children diagnosed with other disabilities. This reported experience is confirmed by the literature discussed in chapter two which examines this issue (Abbeduto et al., 2004; Eisenhower et al., 2005; Phetrasuwan & Shandor Miles, 2009; Woodgate et al., 2008).

In interview, parents in this study characterised ASD behaviours as, often unpredictable and always mercurial. Participants shared how terms, such as, '*high alert*' and '*meltdown*' were used by the family almost daily. '*High alert*' signified the possibility of volatile behaviours from the ASD child. Parents explained that such behaviours were generated by situations that could occur when the ASD child's routine was interrupted and the child became overwhelmed emotionally or overloaded in respect of sensory processing. Parents recounted the family walking on eggshells and living in fear of the '*dreaded meltdown*', which regularly caused distress for them, the autistic child, and the TD children.

In some instances, parents' explained that a '*meltdown*' could be anticipated and by engaging in what Woodgate et al. (2008) call vigilant parenting, the family actively set about trying to avoid a meltdown. Therefore, all family members adjusted their behaviour – this was called '*high alert*' in some families. Participants stated how during '*high alert*', adjustments required that TD children '*back down*' immediately from a disagreement, tolerate '*slapping*' or '*punching*' without retaliating, or absent themselves completely from the room where tensions were high. Parents explained such instructions to TD children as their attempts to stop the situation from deteriorating into a full-blown meltdown episode, in essence what one mother called '*defusing*' the situation.

Participant mother Marie was parent to three children, one of whom has a diagnosis of autism. The family lived in a large home, located rurally and family members had space to absent themselves at stressful times. Marie's account below gives a window into this kind of management strategy, which was reported as being used by several families:

*'Ok, this is going to be a meltdown ... on a bad day it would be everybody in their corner. Everybody knows right, this is full on, clear ... we are going to be on high alert. Everybody knows to back off and leave him alone ... everybody knows, ok Micah needs this time now, we need to get out of the room, close the doors, leave him alone...'*

As a number of parents did, participant father, Hugh, reflected on the unfairness of the situation for the TD children in the family stating:

*'I can see as he gets older and stronger - and he pulls Hope by the hair ... sometimes we say, 'Just give it to him,' and it's exactly the wrong thing to do. We need to pick our battles with him...'*

At other times, parents stated that the onset of a meltdown episode was sudden and well underway before the family realized what was happening. It was asserted by parents in interview that a 'meltdown' could include anything from screaming tantrums to physical attacks on other members of the family. Of 13 participant families, 13 mentioned eating problems and/or clothing issues related to sensory defensiveness; sleeping issues related to hyperactivity; and 'hitting', 'pushing', 'biting', 'slapping', 'pulling hair' 'kicking' or 'punching' related to noncompliance and self injury – each as hallmarks of a meltdown. The features of meltdowns reported by parents and children in the present study, were very representative of existing research which, documents the range of autistic behaviours that present in the ASD spectrum (Benderix & Siveberg, 2007; Hellings et al., 2005; Johnson & Rodriguez, 2013; Matson, 2009).

Participant parents in this present study explained how the autistic child's behaviour could be directed at parents or TD children, or it could take the form of self-harm for the ASD child. A meltdown could happen, day or night and in or outside of the home. In one participant family, where two of the children had a diagnosis of ASD, the mother described how, despite several home visits from a behavioural therapist, she had yet to find a way to calm or redirect one of the ASD child's meltdowns once it was underway.

Parents shared how, during these meltdown episodes, all family activities in that moment came to a halt, with the management of the meltdown and the autistic child becoming the

only focus. Parents added that the TD child was often caught in the crossfire and became the object of the parents' frustrations in these circumstances. One mother, Janice, described managing an episode as follows:

*'With Jill (ASD child)... she'd act up and act out ... everything was 'Get away from the baby!!!' ... and he didn't really understand ...she would have flipped out, and I'd be 'Don't touch her!!!'*

According to participant accounts, the TD children in the family were either, recruited to help manage the situation – *'like getting his blanket or like getting a drink for him'* or alternatively they were sent away while a parent managed it. Many parents said that if the family were out socially, the meltdown heralded an immediate end to an activity and a return home. Kate described a family day out as follows:

*'We went to an adventure park because Kyle wanted to go. We left Kim behind and we thought we'll just take Karl - have only one to manage. And the sensory issues that Karl had were too great, the noise, the lights, everything else - we had to leave. And poor Kyle didn't get this day out'.*

As noted elsewhere, the current study found that family life in the context of ASD almost guaranteed high stress situations daily (Benson & Karlof, 2009; Phetrasuwan, & Shandor - Miles, 2009; Gray, 2002.). Despite adaptive coping strategies designed to moderate stress, participant parents reported that their ability to meet the needs of typically developing children in the household could fluctuate significantly and unpredictably. Reflecting accounts in extant literature, participant parents reported that stress at home derived primarily from the challenging behaviours that are often symptomatic of ASD as outlined earlier such as; physical aggression directed at others, self-injury, destruction of property, hyperactivity, and verbal aggression (Benderix & Siveberg, 2007; Hellings et al., 2005; Johnson & Rodriguez, 2013; Matson, 2009).

All parents referenced their autistic child needing constant supervision and care, regardless of whether they were having a good or 'tricky' day. Parents described planning the routine of the day and adjudicating exchanges between the children continuously to try to ensure that a good day did not deteriorate into a difficult one. Words used by parents to describe the emotional climate at home on a difficult day included *'tense'*, *'difficult'*, *'rough'*, *'chaos'*, *'loud'*, *'emotional'* - with *'stressful'* being the most frequently used descriptor. One mother, Marie, described how such monitoring was essential to preserve a calm home environment because a meltdown had the potential to upset everyone in the home for the day. Marie added:



*Autism is a horrible thing because he'll have a meltdown and hurt and damage or kick people or break the things and then he breezes in half an hour later as if nothing ever happened and you are left dealing with the chaos ...'*

Participant accounts suggested that the fact that parents feel that they are frequently 'dealing with chaos' informs their parenting of TD children and this issue is explored in the next section.

### **Parenting in the Context of ASD**

There are several existing studies which examine the amplification of the ordinary 'push and pull' of parenting that can happen in the context of chronic health conditions (Deatrick et al., 1988; Ray, 2002; Rempel & Harrison, 2007; Woodgate et al., 2008). Ray (2002: 427) terms this amplification, '*parenting plus*', Rempel & Harrison (2007: 824), '*extraordinary parenting*', with Woodgate et al. (2008: 1079) calling it '*vigilant parenting*'. Each term is anchored in the belief that established aspects of parenting may be made more challenging because of the uncertainty endemic to some chronic health conditions, such as autism. To manage this, parents often consciously work to curtail the consequences of their child's condition by strategizing with regard to relationships, planning, nurturing, daily interactions, and discipline. As a result, these parents can become what Woodgate et al. (2008: 1079) call '*super parents*' – proactive and perpetually vigilant.

In the current study, parents shared how being a 'super parent' affected their wellbeing on a personal level. Further, they demonstrated great awareness by reflecting upon how this in turn manifested in how they parented their typically developing children as Smith et al. (2010) below have previously found. The majority of participant parents were self-critical in relation to their parenting and were particularly concerned about their TD children, with many expressing anxieties about their ability to meet the needs of their TD children in a consistent and sensitive manner.

Smith et al. (2010) examined the daily lives of mothers and found that mothers of children with autism report significantly lower levels of positive affect and significantly higher levels of negative affect on an average day when compared to mothers who parent without a disabled child. In addition, these mothers reported twice as much fatigue and twice as many arguments in the home, all of which affected how they parented – a stark contrast to comparison mothers. In the current study, participant mothers and fathers reported

comparable experiences of daily stress in their respective parental roles, which too manifested in their interactions with their TD children. Claire shared that she had a difficult relationship with her TD child and while she reported doing her *'best'*, she said that friction with the TD child was relentless. Claire described this as follows: *'I'm always on edge ... we just always seem to be like, you know, there are cogs in the wheel that aren't rubbing quite - it's not smooth'*. This experience was not particular to mothers. Participant father, Frank, summed up a similar dilemma saying, *'You're narky and you're tired. You're grumpy ... you're less tolerant, I suppose, to the other kids.'*

In addition to this and similarly mirroring existing findings, participant parents reported erratic sleep patterns for all family members, restraints on family recreational activities, limits on career aspirations, restrictions on family holidays and social activities, and financial constraints could all combine to cause considerable stress and distress to every member of the family and create an emotional climate in the home that was precariously unpredictable (Keenan et al., 2007; O'Moore, 1978). The ways in which this emotional climate informs parenting are discussed in the next section.

### **The interaction of the Emotional Climate and Parenting**

All participating parents in this study reported that how they parented was inextricably linked to the emotional climate in the home on any given day. This, by default, was invariably linked to the autistic child in the family. When compared to families of children with other disabilities, stressors for families of autistic children are unique, related to the particular profile of deficits related to the condition (Bromley et. al. 2004; Lovejoy et al., 2000; Woodgate et al., 2008). As existing research finds, the majority of parents in the current study reported feeling distress, depression, and significant stress regularly. (Benson & Karlof, 2009; Phetrasuwan & Shandor Miles, 2009; Smith et al., 2010).

Exhaustion that resulted from lack of sleep was cited by parents as the most significant contributing factor related to their mood and stress levels. Parents added that this then determined how they related to their partner and the TD children in the household. Sleep disturbance is common among autistic children. Research finds that this may be related to the fact that hyperactivity is the most commonly reported comorbidity of ASD (Bauman, 2010). As found in existing studies, participant parents in this study reported that, despite

consistent sleep hygiene practices, they could never depend upon an undisturbed night of sleep (Henderson et al., 2011; Herrmann, 2016).

Parents in this study explained that sleep disturbance for the ASD child manifested mainly a, night wakings after the child had gone to sleep and early morning wakings. Many parents spoke of sleep being regularly disrupted because of the autistic child *'waking up at 2 o'clock in the morning ... constantly going'*. This could happen for several consecutive nights. Once a child had woken, parents recounted that they could not predict what would follow but *'screaming', 'singing', 'crying', 'playing',* and *'meltdowns'* were all reported as possibilities. Parents stated how this could continue for several hours and how usually TD siblings were woken up because of it. Participants added that getting through the following day, having had little or no sleep throughout the night, could feel like *'torture'*. Participant mother, Fiona, explained this, best saying:

*'I cannot overcome the lack of sleep ... I'm emotional ... they (TD children) know ... I'm losing my mind here I'm so tired ... me and Frank ... we nearly kill each ... and then there's a sense then, generally - it's between me and Frank, that we're not going to get out of this alive...'*

One family reported trying to combat this issue by building a sleeping room, so that TD children could sleep difficult nights and attend school rested the following day. Another mother described how the autistic child was allowed to sleep anywhere he liked, including his TD siblings rooms, because getting him to go to sleep was the only objective. Yet another father, Niall, explained his child's attachment to a tiny Sylvanian Family toy that was key to their bedtime routine with the autistic child. He added wryly: *'He's going around with this little Sylvanian baby thing ... I don't know how he hasn't lost it. But if that gets lost we are in trouble'*.

As found by Johnson and Rodriguez (2013), parents of children with ASD have a variety of mechanisms in place to manage and minimize challenging autistic behaviours. Behaviour management techniques span consequence based strategies for the autistic child, to managing the home environment and minimize precursors to undesirable behaviours. In the current study, it became clear that managing the home environment was something that was led by the parent and required the cooperation of TD children. Given their chronic fatigue, parents described military like arrangements and planning in efforts to *'stay ahead of the game'* and make their day predictable and practicable. Nuala explained:

*'If everything's organised, everything stays calm. Everybody knows the sequence, what's happening... otherwise chaos might ensue, absolute chaos. Bad humour, rattiness amongst everybody - unorganised, it's harder to function'.*

The proactive vigilance of *'super parenting'*, outlined by Woodgate et al. (2008), was evident in how parents prepared for each day. Participant mother, Liz, laughed as she confided that there are days where, *'I think I woke up in the army'*. Being organized for parents included strategies such as, always greeting their autistic child first in the morning to get the day off to a good start. Liz explained: *'I'll always say good morning to him first because ... if you wake him up in a happy humour, he'll stick in a happy humour'*.

Managing the home environment additionally involved adhering to established routines, preparing the autistic child in advance of any change to that routine, managing noise levels in the home, having fidget toys at hand for the autistic child at all times, time tabling TV to avoid arguments between the autistic child and the TD sibling, and always having the foods that the autistic child ate prepared, especially if the family were eating out.

Efforts to manage the home environment could also mean allowing the autistic child behaviours that TD siblings were not allowed - for example, one mother shared how her autistic child was not expected to do chores in the home but TD children were, while another said she allowed her autistic child a toy at the dinner table when TD siblings were not permitted the same. As noted elsewhere, this kind of differential parenting can have long-term effects on TD siblings, but parents argued that it was necessary, if not unavoidable on occasion (Boyle et al., 2004; Chan & Goh, 2014; McHale et al., 1984) Two parents – one mother and one father from different families – each used the phrase *'We need to pick our battles'* to explain this approach to parenting. Parents expressed that it was imperative to ensure these strategies were in place to avoid a *'meltdown'*.

Fathers' reports about organizing and planning had an additional dimension. As existing research demonstrates, for fathers, planning and organisation is a central component of problem focused coping as outlined by Lazarus and Folkman (1984). This kind of coping allows fathers act as an emotional and economical support for the family (Burrell et al., 2017). Fathers in the present study reported how strict planning served to reduce stress for their partner and TD children, and ensured they could go to work daily and on time with minimal disruption. Participant father, Derek, spoke of the need to have, *'a lot of planning in place ... there are definitely things that a lot of families would do that you can't or that are way more challenging'*.

The father's role as economic provider was vital for participant families in the current study, given that only one mother reported that she worked full time outside of the home. Of remaining mothers, the care of the autistic child meant that seven mothers did not work at all and four mothers worked reduced hours. In an Irish context, parents of disabled children are less likely to be employed and have lower incomes according to research (Gallagher & Hannigan, 2014). This finding reflects findings from Canada, which found that, on average, mothers of autistic children are 6% less likely to be employed than mothers of children with no health conditions, and in addition, family earnings in families where a child is autistic are 28% less than those of children with no health conditions (Cidav et al., 2012). The economic restraints imposed as a result were reported as an additional source of stress for parents in this current study who reported regularly prioritising the needs of the autistic child above the needs of the TD child where finances were concerned.

Many fathers in the present study spoke of the demands of work and the interaction of that with their home life. One father described sitting in his car in the driveway, tired after a day at work, sometimes dreading what might greet him when he turned the key in the latch. Yet another spoke of his increased workload designed to compensate for his wife's resignation from work, which followed diagnosis of their autistic child. Frank explained his exhaustion and the impact this had upon his role as a parent:

*'I'm working Monday to Saturday ... I'm not getting any time with him (TD child) at all ... I suppose you're on edge ... you're just burning the candle at both ends. You're tired, physically tired and you're mentally tired'.*

As a result of chronic fatigue and stress, most parents described how they were often 'snappy' when parenting their TD children. Parents explained that caretaking tasks involving their autistic child monopolized their time and energy (Dabrowska & Pisula, 2010; Plant & Sanders, 2007), often leaving them easily irritated. While parents stated their belief that they were mostly attuned to their typically developing child's needs, they added that sensitivity to TD children - when managing stressful situations - could evaporate in the moment.

This was particularly reported by mothers who remained at home as the primary caretaker of the children. As such, these mothers were particularly exposed to the challenging

behaviours of the autistic child as existing research confirms (Gray, 2003; Pepperell et al., 2018). Gray (2003: 635) goes so far as to characterize the care given by mothers as fathers having respite care five days a week. Confirming this, Dabrowska and Pisula (2010) examined levels of parenting stress among sets of parents who had an autistic child and compared their levels to parents who had a child diagnosed with Down's Syndrome and those with only typically developing children. No differences were found between parent sets, except notably mothers of autistic children who scored higher than fathers of autistic children in parental stress levels (2010: 266).

Given that mothers tend to be the primary caretaker in the home where a child had a diagnosis of ASD (Pepperell et al., 2018; Wayment & Brookshire, 2018; Woodgate et al., 2008), mothers are often the focus of research projects and so additional research studies also report elevated levels of stress and depression in particular for mothers of autistic children when compared to mothers raising children with a different disability such as Down's Syndrome or a mother raising children without disabilities (Abbeduto et al., 2004; Eisenhower et al., 2005; Phetrasuwan & Shandor Miles, 2009; Woodgate et al., 2008). The key reason for this may be the exceptional profile of deficits associated with the condition discussed in the Chapter One (Bauman, 2010) and findings cited earlier around mother's increased exposure to the behaviours of their autistic child (Gray, 2003; Pepperell et al., 2018).

It is not surprising then, that in the current study the manifestation of stress in interactions with TD children was most prevalent in mother's accounts of parenting. One mother, Denise, recalled an occasion where the family was shopping. She remembered her autistic son, John, *'began hand flapping and hitting himself and crying ... Elena began to hit John and she ended up the one in trouble'*. Denise added that on reflection, she felt guilty because she had been so unfair, stating that her TD child, Elena, *'hadn't really done anything wrong and after when I asked her why she hit her brother she said she was trying to help him by making him stop'*.

The impossible task of being 'fair' to all of the children, in a family situation that was experienced by parents as inherently unfair, was a concern reported frequently. Participant parents here as in previous studies, described how their autistic child's needs made impartial parenting difficult and could increase negative interactions with the TD children in the family (Chan & Goh, 2014; Smith et al., 2010). Participant mothers shared how the management of the autistic child, and the constant explaining and negotiation with TD

children that resulted from this, impacted their psychological wellbeing also, as discussed in the next section.

### **Parental Mental Health**

The significance of the wellbeing of mothers in this context in particular, has been the focus of previous research. It is strongly indicated in the research literature that parental stress and mental health impact critical aspects of coping and parenting (Dabrowska & Pisula, 2010; Meirsschaut et al., 2010; Quintero & McIntyre 2010; Woolfolk & Perry, 2011). Quintero & McIntyre (2010) examined maternal wellbeing in families living with autism, noting that the mothers they studied reported significantly higher stress and depressive symptomology, which may ultimately have implications for their TD children. This was particularly evident in mothers' accounts in the current study.

Managing depression and stress proved to be a staple of daily life for the majority of participants in this study, and was reported most frequently by mothers. Echoing Quintero & McIntyre (2010) and Gray (2003), participant mothers in the current study openly shared that they experienced depression and notable stress connected to parenting - and these experiences were communicated in interview in highly emotional language. Several mothers had concerns about their own wellbeing and their ability to parent well. Many spoke of feeling, *'tired'*, *'stressed'*, *'sad'* and regularly *'crying'*. Some explained that their patience with their TD children ran short very quickly on a difficult day at home. Mothers also described how ordinary frustrations could also take on disproportionate significance considering the stresses that they live with, as outlined earlier. In talking about disproportionate reactions, one mother, Janice, said, *'I'm like homicidal maniac, if the freezer over-freezes ... something like that can just totally overwhelm me'*. Another mother, Claire, described *'going bananas'* about her TD child's reluctance to do his chores stating, *'I don't want to fight with him but he'd just drive you to insanity'*. Over reacting to children being children was something that parents were aware of and this was mentioned frequently particularly by mothers. However, most participant parents made the connection between their overreactions and the stress they were under, which resulted from situations that *'would be to do mostly with ... meltdowns'*.

For children, warm responsive parenting results in secure attachments, superior social skills and strong peer relationships (Ainsworth et al., 2015; Parke & Buriel, 2006). However, parental depression has the potential to be one of the most negative influences on a child's outcomes (Woolfolk & Perry, 2011) and has implications for attachment relationships. Depression often manifests itself through family processes such as parenting, therefore children in a family where a parent is depressed as a result of coping with a child diagnosed with autism, may be especially exposed to its negative effects. Several parents in the current study were acutely aware of this and some took measures to address it, as Helen relayed in an emotional exchange:

*'... it was kind of difficult ... I was all over the place ... And I did counselling every week for an hour for 6 months. And it was the best thing ever ... I'm getting upset now ... all I want is for them to have a happy childhood as much as I can, and I just don't want to fuck them up basically.'*

Furthermore, Meirsschaut et al. (2010: 667) found that it was mothers who felt most guilty about 'not doing enough' for their TD child than for their child with ASD. In the present study, all parents recognized that raising an autistic child could take its toll on their mental health and energy levels, which in turn could have a negative effect in their interactions with their TD children. Helen, for example, explained that on a tricky day, when her autistic child is difficult to manage:

*'I end up giving out to the other two (TD children) as well. And they can feel it and then I might be very short with them and I end up ... feeling bad about it and I usually try and ... I explain listen I'm sorry I shouted, I was just a bit frustrated, because Henry (ASD child) wouldn't cooperate'.*

While both mothers and fathers expressed guilt that they often did not have the time or energy for their TD child, many fathers rationalized their guilt, to some extent, by arguing that given that they were 'in work all day', it was something beyond their control. Gray (2003), when examining coping and gender, similarly found that fathers who assumed the traditional role of breadwinner – as all fathers interviewed in the current study did – expressed less negative emotions about their parenting experiences by suppressing or rationalising them. Gray (2003: 635) argues that the role of work creates a role for fathers separate from their family's domestic life. Given this, fathers' accounts in the current study suggested that, although they could feel guilty about time spent with their TD child, they were more forgiving of themselves because that guilt was tempered by the belief that they had no choice but to be at work.



Fathers were however less forgiving of themselves and expressed greater accountability when it came to their typically developing children getting *'the brunt'* of, or *'the fallout'* from their frustrations. Both fathers and mothers said that they were aware that they regularly managed their own distress by venting inappropriately on their TD children. One father, Larry, said of his 6-year-old typically developing child: *'I expect her to understand things and she doesn't. Or I will tell her to do something and then if she doesn't I would raise my voice at her. I sort of take it out on her a little bit.'* Although Larry, and other parents, articulated insight into what they were doing and why they were doing it, they added that insight did not mitigate the frustration they experienced in the moment. Therefore, although in interview, Larry could acknowledge the behaviour as unfair to the TD child, he admitted persisting in it. This was a common occurrence among parents who spoke of their awareness of unfairly, *'giving out to'*, *'screaming at'* or *'fighting with'* their non-autistic child as a direct result of something the autistic child had done or because of a meltdown. One mother, Liz, stated simply: *'I have a lot of guilt when it comes to Amy because of her brother ... you know that kind of mammy guilt ... it's very hard.'*

Parents also shared that, even on a 'special day', the stress of life as they encountered it meant that their TD child's needs were always at risk of being displaced. Kate explained, *'His own birthday ... we left his own birthday party early ... he was there, but his own mother and father were gone because his sister and brother needed to be brought home'*. Narratives further revealed that despite a 'good day'—the constant vigilance that accompanied the threat of a meltdown, left parents constantly exhausted, tense and agitated. (Dabrowska & Pisula, 2010; Eisenhower et al., 2005; Smith et al., 2010) Parents described how they attempted self-care in relation to their mental health by taking time out as a couple. However, even when they managed a night out alone, the possibility of a meltdown still loomed large so they could never quite relax fully. One father, Frank, explained that he felt he was still learning to parent his autistic child and he still found it difficult. As a result, he explained that handing that parenting role to another, even temporarily, caused significant anxiety. He explained this as follows:

*'We leave him with a baby sitter but ... you're worried. Of course you're worried- all the time like – if he had a meltdown or they wouldn't be able to control him like. Or he hurt himself because he does hurt himself a lot like or he can do, you know. Like banging his head and biting himself.'*

Though Kate's family experience referenced above was notable, another mother, Helen, explained that even in the absence of a meltdown, the 'eclipsing' of the typically

developing child could happen in small ways, lost in the bustle of daily family life. Helen went on to say: *‘What I realised was, that Hope was falling through the cracks, not getting any time with anybody and she was just fitting in ...’*.

The constant worry about TD children was reported by parents as exacerbating mental health issues such as generalised anxiety and guilt. Of participant parents, 18 of 20 expressed concerns related to their mental health and fears that they were faring badly when it came to parenting their typically developing child (Meirsschaut et al., 2010). Speaking of her efficacy related to parenting, one mother, Claire, stated she was aware that *‘a lot of the parenting isn’t as good as it probably should be’*. This was an anxiety commonly acknowledged by parents, but was qualified by the belief that the autistic child *‘needs me more’*. This belief, frequently stated by participant parents, regularly resulted in differential parenting, and this is discussed in the section that follows.

### **Differential Parenting**

Similar to findings in previous studies, often participant parents in the current study believed that they necessarily *‘have to spend more time and energy and effort’* with their autistic child, as the child’s ASD needs require them to do so, therefore there the relationship with the TD child to could suffer as a result (Chan & Goh, 2014, Smith et al., 2010). This strongly held belief was central to parents’ reported experiences, as was the feeling that they were powerless to change this. Parents’ preoccupation with their autistic child became apparent in interview also as participants sometimes struggled to answer questions about their relationship with the TD child in the family. On several occasions, quite unaware, parents lapsed into talking about and focusing on the autistic child while speaking about the TD child.

Due to the context of the parent-child relationship in the current study, both parent and child narratives demonstrated that differential parenting regularly took place for a variety of reasons linked to the autistic child’s needs. Existing research finds that in families with children with disabilities there is increased differential parenting, with the differentiation most often favouring the child with the disability (Lobato et al., 1991; McHale and Pawletko, 1992). The consequences of this can vary. According to Boyle et al. (2004: 16) those who are not the ‘favoured’ child may experience the self as diminished and less worthy of love. However negative effects may diminish if a child understands why differentiation happens and experiences the difference as being fair (Kowal et al., 1997).

Reiterating Kowal et al. (1997), McHale and Pawletko (1992) found that differential parenting does not always have negative consequences for TD siblings if the TD sibling can appreciate and legitimise the parents' decisions in their own mind.

Given the needs of their autistic child, many parents expressed sentiments such as those outlined above and they repeatedly emphasised that they felt they had little choice in how they managed their home and their relationships with their TD children. They believed the TD children, much of the time, could '*understand*' why their autistic sibling was the focus and the differential parenting that occurred as a result. On occasion, for good measure, parents described feeling the need to underscore explicitly for typically developing siblings that, as parents, they were not playing favourites – explaining that their autistic sibling's needs required them to respond as they did. This was reported by parents as their attempt to minimize negative consequences for the TD child (Kowal et al., 1997; McHale and Pawletko, 1992). Participant father Robert communicated his experience of explaining differential parenting to his TD child as follows: '*I know Amy thinks that sometimes I favour Conor ... I try not to or I don't consciously do it - I have to explain that we have to deal with that, we are not taking away from you*'. Participant mother, Emer, similarly said of differentiating between her children, '*We have had to have that conversation a lot over time and I had to repeat it a lot ... I have to remind them that I am not playing favourites.*'

Parents acknowledged that despite their best efforts, they believed that their typically developing children regularly felt a sense of injustice because of differential parenting. They added their belief that TD children could feel negatively about their autistic sibling at times because of this. This finding is corroborated by existing research (Aronson, 2009; Benderix & Sivberg, 2007; Chan & Goh, 2014, Hutton, 2005). One mother, Kate, articulated this belief directly, without equivocation, stating: '*I'm sure all those things sit with him and I am sure he feels a bit hard done by. I feel hard done by for him*'.

As Meirsschaut et al. (2010) found, the need for quality time with typically developing children in the family was something parents, especially mothers, reported being aware of. It was something they clearly stated and clearly wanted. One mother Liz observed, '*I don't say it to her that I don't spend time, but I feel it myself that I don't spend enough time with her*'. As existing literature findings suggest, in an often stressful home, parents said they felt a pressure to be '*extraordinary parents*' (Rempel & Harrison, 2007: 824) if they were to be prepared for all eventualities. Many parents in this study reported finding this exhausting. Several parents explained that spending time with their TD children meant

anticipating problems with their autistic child or, as one mother, Nuala, said: *'putting things in place ... so that if things get too much ... I have a backup plan'*.

Parents reported how on occasion they tried to carve out time for the TD child is an attempt to compensate for differential parenting. Many explained that stress levels were such that, making plans for one to one time with their typically developing child, and putting everything possible in place to try to guarantee it happened, meant they had no time for their own interests. Therefore, time with the TD child in itself, began to feel like just another pressure. Participant father, Mark, explained, *'If you get that time, you just want to ... I do a lot of running then I stopped - but now I've started again. I am using that as my 'me' time'*. The majority of parents regularly articulated their difficulty with consistently setting aside time for the typically developing children, even on good day. One mother Kate stated this most succinctly stating of her TD child, *'He has less time. Straightaway there's less time with us. And that's just out of anybody's control. We do our best to try'*.

Together time with TD children was reported by many parents as something that needed to be planned, but frequently their time together was impromptu. Several parents explained that the 'impromptu' approach was preferable, as it reduced the frequency of times when circumstances beyond their control resulted in disappointment for their TD child. The *'parenting plus'* (Ray, 2002: 427) exhibited by most parents in this study had its limits, and parents were realistically aware of this. Therefore, if a moment presented where the parent could spend some one on one time with their TD child, it was taken advantage of because, as one mother, Fiona, explained, *'I can't schedule anything'*, because it could result in, *'Oh my God I'm telling the children I'm going to do this and now we can't go!'*

In addition, participant parents described how planned family outings involved *'splitting'* the family whereby one parent took charge of parenting the autistic child and the other attended to the remaining children so that they got some one to one parent time. As previously noted, most families reported that the mother knew the autistic child best, as she was most experienced in managing the child's behaviours (Gray, 2003; Pepperell et al., 2018), so more often than not, the autistic child became her 'charge' and the TD children were cared for by their father. However, some parents also did the opposite and then 'swapped' to try to ensure that TD children had at least some time with each parent. One mother, Liz, explained:

*'When we do go out anywhere we tend to split up – Rob will stay with Conor and I'll go with Amy ... and I can give her attention ... then we'll kinda swap ... it's always been the case, if we do anything, or go anywhere, we always split in twos'.*

All parents emphasized that social activities undertaken as a family were customarily dictated by what the autistic child could or could not tolerate in terms of socializing. This resulted in the TD sibling having little input into what the family did together socially. One mother, Helen, explained *'normally whatever we do is tailored to make sure that Henry will cope with it ...'* Reflecting existing research findings (Woodgate et al., 2008), another mother, Nuala, added how these limitations can result in isolation for the family, and a particular feeling of isolation as a parent:

*'Social situations are difficult. Bringing Noah to people's houses is difficult. Eating with people is difficult, family parties are difficult, there's a lot of things that are difficult so we tend not to do them'.*

This isolation was reported as effecting TD children also. One mother, Denise, said her ASD child's behaviours had made her *'very wary, even of play dates for Elena'*. She went on to explain that, as a parent, she has always been cautious, because unless people know her family well and know the home, there is the potential for problems. She gave this example, *'If John (ASD child) comes out of the toilet with his trousers around his ankles, and a visiting friend of Elena's repeats that to a parent, then I would be concerned that I would find the police on my doorstep'*. She added that anxieties like this restrict Elena's social life and add to the family's isolation. Not all parents reported feeling very isolated, however some degree of self-imposed restriction was put in place by several families to defend against potential problems. Researchers explain this phenomenon as the family's efforts to protect their autistic child from a world that does not understand autism. The resulting sense of isolation sees families completely focused on the autistic child's world instead (Gray, 1998; Woodgate et al., 2008)

When it came to differential parenting, all participants articulated a central dilemma - they wanted to, and intended to be attentive and engaged with all of their children in an equitable manner - yet, they explained that the reality of their situation took over and this did not always happen as they would like. The main consensus from parents' narratives was that the normal push and pull of parenting became amplified when autism had to be accommodated (Deatrick et al., 1988; Ray, 2002; Rempel & Harrison, 2007; Woodgate et al., 2008). Several parents recounted how good intentions could easily give way to stress, fatigue, anger, or sheer frustration. The needs of the autistic child regularly ensured that the

needs of the TD children were overlooked, unmet, or met sporadically. One father, Hugh, stated,

*'It happens so passively, he takes up the time before you know it ... and then the other kids are coming in and ask you a simple question and either you don't hear them, because you are focused on Henry or - but kids are accepting ... they don't know what they are missing ... I think they are resilient, I think any kid in that situation would be resilient.'*

An examination of participant narratives revealed some parents' assertions that TD children were resilient because they were accustomed to living in this way. The ubiquity of this belief suggested that it may have served as a buffer for parents, defending against their fears about their TD child - or alternatively this belief may have been used by parents to defend against the guilt they confided in interview. Additionally, it could be argued that such beliefs acted as parents' indirect attempts to protect the TD sibling. Certainly, in research around the notion of self fulfilling prophecy, the finding that *'When we expect certain behaviours of others, we are likely to act in ways that make the expected behaviour more likely to occur'* (Rosenthal & Babad, 1985: 36) may underpin such statements by parents, in that, they create an expectation of the TD sibling - namely that they be resilient - and if fulfilled, this can be protective for the TD sibling in the long term. Parents' additional attempts to redress differential parenting and protect the TD sibling were also evident in their use of social support and this is discussed in the next section.

## **Parenting and Social Support**

Despite challenges reported and discussed here, many participants felt the pressures of their situation were compensated for, to some extent. All participating parents indicated that their lives were busy and often stressful but their experiences were tempered by good days. Speaking of all his children, one father, Mark, quipped, *'We are not the Waltons here! I suppose on a fun day - we'd have some music or they could be running around or kicking football in the house'*. Parents' definitions of good days at home often referred to the autistic child being in *'good form'* or the child having slept. Parents used words and phrases like, *'no melt downs'*, *'no screeching or screaming'*, *'everything just flows'*, *'relaxed'*, *'happy'*, *'calm'*, *'quiet'*, to describe days at home that were experienced as enjoyable. On these days, parents felt the family was *'strong together'* and *'cohesive'*. One

father, Ciarán, went so far as to say, *'Sometimes it's even a bit spiritual - that we feel a connection there without saying much ... that would be on a good day'*.

Studies that examine the adjustment of families in the context of disability note that the severity of a child's diagnosis is not consistently correlated to how a family will cope (Baker et al., 2002; Bayat, 2007). Coping is however enhanced by enabling strategies related to functional coping; these include, cognitive processes characterised by optimistic attitudes, the constructive management of emotions, and open, empathetic communication. Research strongly indicates that these processes are anchored in resilience and act as protective factors in a family under stress (King et al., 2006; Scorgie et al., 1996), which in turn benefits TD siblings in the family.

Accounts from many parents in the current study showed they often exhibited these kinds of resilient enabling strategies in their approaches to family life and parenting. Participant parents remained optimistically realistic about the challenges they face and were eager to cite the positives of their situation. Participants shared how their autistic child often exhibited positive behaviours and could be happy and co-operative with both themselves and their TD siblings when they were related to in appropriate ways. Parents were equally positive about their TD children. All participants perceived each of their children to be *'funny'*, *'affectionate'*, *'intelligent'*, and *'loving'*, with parents descriptors of TD children being overwhelmingly positive.

Many parents spoke of experiencing autism as a *'journey'* that the all of family were on together, learning and adjusting as they progressed. All parents added their feeling that they had progressed from the struggles they encountered after the initial diagnosis. In relation to supporting the TD sibling, participants spoke of different strategies like getting involved in their TD child's sports coaching or occasionally taking the TD child out of school early in order to actively create opportunities where the TD child would be their only focus. One father, Derek, summed up his approach to family life as follows:

*'I think you'd need to try and deliberately have something positive and fun ... Because a lot of the time so much of your attention and your time is diverted ... You need to have that separate space where the other child is the centre of attention, kids love being centre of attention. And if they are starved of that, I think that's where you start to get into negative space'*.

The constructive management of emotions by parents (King et al., 2009; Walsh, 2011) was also evident in reported dialogues between parent and the TD child. Parents reported open communication around some issues that directly affected their relationship such as differential parenting and discipline. Moreover, parent narratives suggested that some frequently tried to listen to the feelings of the TD child about their autistic sibling and validate those feelings with acknowledgement and support. Kate explained this as follows:

*'We have explained it to him, look Kyle we have tried to discipline but it just doesn't work. He (ASD child) just doesn't have the understanding for the bold step or timeout ... this is the way that we have to do it ... he (TD child) accepts it now. He understands that we have tried everything. He has seen us try.'*

As existing research finds, and as confirmed by the current study, enjoyable and intimate interactions in the face of challenges, were often constructed by parent and TD child in the most ordinary of ways (Chan & Goh, 2014). Most parents explained how certain everyday activities became precious moments. Driving the TD children to school or to an after school activity became *'our talking time'*; putting the TD children to bed became, an opportunity for *'a chat'*. These one to one moments, recounted by participants, took on a special significance in a sometimes difficult situation where parents *'just want the kids to be happy'*. These moments of closeness also served to amplify the parents' awareness of the TD child's needs, as one mother, Sue, explained:

*'We went to a football match and when we were coming back we stopped for an ice cream and ... he said 'Mam that was one of the best days ever that you and me spent and you know what, it really hit me because ... he's eight and that's his first time actually feeling that him and me had done that as a day thing together, just the two of us.'*

The various strategies described above were reported by parents as easier to achieve when they had some degree of social support. Most parents referenced the importance of social support in connection with functional coping, that is, in their attempts to manage family life generally, and time with their TD children specifically.

Schopler and Mesibov (1984: 297) discuss the role of formal social supports, such as those provided through a formalised group or organisation and informal social support that span networks, which can include, extended family members, friends, and neighbours. In the current study there were parents who said that they had the support of extended family and friends because of their ASD child's needs, with grandparents often stepping into the kind of informal support role for the family described by Schopler and Mesibov (1984: 297).



As in other studies, there were also parents in this study who stated that they felt disconnected from extended family and friends because of their ASD child's needs. This can happen when autism is seen and understood as misbehaviour by distal family members causing parents to feel judged unfairly (Bartak, 2011; Gray, 2002; Woodgate et al., 2008).

In the current study, the inability of family to understand autistic behaviours was reported in a notable way in only one case. One mother, Nuala, relayed an exchange with her own mother, the autistic child's grandmother at a family christening. Nuala reported that the grandmother's belief was that the autistic child needed nothing more than, *'a good slap ... and I find that very difficult ... so I rather just stay away from it ... 'cos I feel people are watching and I feel judgmental eyes'*. Woodgate et al. (2008: 1078) note that the isolation, which can result from such stigmatization, ensures that, 'living in a world of our own' becomes the defining statement which describes what it is like to be a parent with a child with autism'. Nuala reported that the informal support of her husband's family compensated for her own family's absence to a large extent, as did the family's engagement with an ASD support group, each of which was key in managing some one-to-one time with her TD child.

The role of a support group in the lives of families raising an autistic child was explored by Mandell and Salzer (2007). They surveyed 1,005 caregivers of autistic children to ascertain the benefits for families who engage with support groups. The benefits noted in the study included, information-sharing and a secure environment in which the family member can offer and obtain support – each benefit underpinned by the fact that all members in the group fully identified with the experiences of the others. To participate in the current study it was required that the family be engaged with a support group therefore the participant families here were each linked in with various ASD support groups around Ireland. Participation in support groups was reported by parents as indispensable in the lives of families serving as it did to make them feel less alone in their experiences, in addition to supporting parents' use of enabling strategies related to functional coping that in turn act as protective factors in a family under stress as found previously (Clifford and Minnes, 2013; King et al., 2006; Scorgie et al., 1996)

In speaking of the benefits provided by her family's support group, Sue described how *'They have been our absolute saviour in many ways'*. Many parents felt as Sue did. Furthermore, several parents described a social life closely linked into their support group that benefited their TD child. Liz explained:

*'We are in ... an autism support group, they have a lot of children in it that are siblings of children with autism ... Amy will - she'll hang out, sometimes ... they all hang out together there and they talk ... they have a hill walk this weekend ... she likes going out to stuff'.*

Four families reported that they believed their relationship with their TD child could be supported further if they had regular access to respite care. There is evidence to suggest that the provision of respite care and various support initiatives, enhances parental well being and reduces stress for the family unit (Barker et al., 2011; Tehee et al., 2009). Participant parents spoke of their belief that some kind of respite care would be supportive of their relationship with their typically developing children, in that it would allow the TD child be their sole focus, at least on occasion.

Of 13 families interviewed, two said they had successfully secured respite care; in each case their family situations were exceptional - as research finds is often the case when a family relinquishes care of their autistic child, either occasionally or long term (Nakervis, Rosewarne & Vassos, 2011). The first family reported they had no extended family living locally, and their child had significant deficits associated with ASD that caused exceptional stress for the family. This family had respite care for their autistic child one day each week for 24 hours. The participant mother in this family, Denise, recalled that her TD daughter, Elena, *'counts down the days through the week until Johns goes'* and constantly asks *'When is John going? When is John going? When is John going?'* Denise said that she hears this all week because Elena *'absolutely loves having us to herself for that 24 hours'*.

In the second family, two of the three children in the family had a diagnosis of ASD – one of whom had significant deficits. The mother in this family, Kate, reported that despite being granted respite, the family was yet to actually have the respite promised. She explained her disappointment, especially as she felt it would benefit her TD child so much:

*'I have applied for and got respite hours for both children ... This was 2016 I was awarded this and we still haven't see an hour of it ...and if I just had that ... if I could say to Kyle, today's the day we get home and the others aren't there. That would be huge - if it was just one day a week that he could look forward to'.*

Not all families expressed a desire for respite care. In one particular family, keeping the family unit intact at all times was reported as the parents' main goal. The parents felt that respite care would leave their family incomplete because the autistic child would be excluded from some family experiences and diminish their TD child's relationship with

their autistic sibling. This family expressed that they were not comfortable with this. The father of the family, Frank, explained his feelings as follows:

*'So yeah, if we had more support I think, you know, we'd have more family time but then I suppose - when you leave him (ASD child) out, then don't you leave him out? He's part of your family as well like'.*

Despite some concerns, and notwithstanding the stresses reported by parents in this context, all parents in the current study reported striving towards the planning, nurturing and extraordinary parenting, as identified by Rempel and Harrison (2007). Additionally, all expressed that supports that would allow them one to one time with their TD child was instrumental in achieving this. Kate, mother to three children, two of whom are autistic, mentioned that this seems like such a small request but she felt it was vital for her TD child, *'That's important for both of us. It doesn't matter what we do. He is just happy to be out without them with you'*. Related to this, several parents highlighted the fact that despite good days, selfcare and regardless of social support, they had concerns about the quality of the TD child's childhood experience in general and how this might be affecting their development. This is explored in the next section.

### **Parenting and a 'Happy Childhood' for the TD Sibling**

Studies, which examine childhood experiences and the social-emotional development of typically developing children who have siblings with chronic disabling conditions such as ASD, are broad ranging. Findings vary hugely, with little consensus on the positive and negative effects of growing up with a sibling diagnosed with such a condition so definitive conclusions remain elusive. Research indicates that parents can underestimate the challenges inherent in the experiences of siblings (Glasberg, 2000) and in some cases, despite their efforts, may even engage in behaviours that exacerbate them (Rossiter & Sharpe, 2001; Akhtar et al., 2012). Findings in the literature reveal that there are a number of experiences and feelings that are common to children who have a sibling with additional needs, namely: worry, resentment, sense of isolation/embarrassment, and a sense of needing to be more 'independent' (Bendrix & Sivberg, 2007; Meyer & Vadasy, 2007).

An exploration of parent narratives in the current study revealed that parents were largely aware of their TD children's feelings as outlined above, and they acknowledged that their TD child's childhood was compromised, despite social supports engaged with by the

family. One parent, Derek, stated of his TD son that because of his sibling's autism, *'David's life is limited by practical things that you just have to do'*. Parents cited various concerns related to the quality of their TD child's experience of childhood including: the quality of their parenting; the volatile nature of the climate in the home; violence experienced by the TD child at the hands of the autistic child; lack of parental attention and time; the TD child's precocious independence; and the lack of privacy and space for the TD child.

Across all interviews, the central paradox that every participant parent reported having to manage was their desire that their TD children be children and have a childhood – and in tandem with that, their own need for TD children be 'grown up' in moments where parents felt at breaking point or needed *'to take a break.'* Being 'grown up' was implied by parent accounts as TD children making an infinite number of allowances for their autistic sibling - regardless of what they understood, how they felt, or how old they were. Parent narratives showed that - at the request of parents themselves - caretaking of their autistic sibling by the typically developing child was a frequent occurrence, as were; tolerating embarrassment without comment, accepting differential parenting without complaint and bearing a physical attack without retaliating. Parents accepted that this made childhood difficult and that this was not in the best interests of the TD child who was often afraid of their autistic sibling as a result (Benderix & Sivberg, 2007). This was distressing for both parent and TD child. One mother, Marie, said sadly:

*'I wish I could tell her that she doesn't have to be, you know, scared of Micah (ASD child). I wish I could tell her that there is never going to be a meltdown again ... or that she's not going to get the backlash of me being bloody pissed off with something that Micah has done'.*

At their core, parent narratives indicated that at times of high stress where they had reached their limit, without intending to, they needed the TD child to have no needs, no requirements for themselves, particularly in moments where demand outstripped supply in terms of parenting. Participants' contradictory feelings about these issues became evident in how they spoke about the TD children in the family. Descriptors used by parents to describe times when TD children were compliant included *'good'*, *'intuitive'*, *'nice'*, *'accepting'*, *'caring'*, *'flexible'*, *'insightful'* and *'understanding'*. During stressful times, typically developing children who protested or demanded for themselves were reported by parents as being experienced as *'bold'*, *'frustrating'*, *'hard work'* and *'trouble'*. Implicit in these adjectives is an unintentional script for TD children, which may see their sense of

self under-pinned by the belief that they are only of value when they are compliant or when they are of service to other people which may have implications for their development in the long-term (Chase, 1999; Sahoo & Suar, 2010; West & Keller, 1991). West and Kelleher further argue that in such situations the TD child may ultimately lose, *'any ability to express need or ask for care, yet retains a pervasive, unsatisfied neediness and longing for care'* (West & Keller, 1991: 431).

Hollingsworth et al. (2003) argue that teaching a child responsibility is a very different process to parentification, which essentially brings a premature end to childhood. Whether stress is derived from a mental health issue, family unpredictability due to drug use, or from raising a child with a disability (Chase, 1999), research literature shows that parents struggling to cope can begin to have expectations of TD children that are incongruent with the child's developmental stage or their ability to cope (West & Keller, 1991). This became evident in parent accounts where they acknowledged expecting their TD child to understand all facets of autistic behaviour, asking TD children to help excessively in the home, expecting TD children to prepare meals for themselves, or insisting that TD children take part in ASD related activities and reprimanding them if they objected. In speaking of her TD son, Claire went on to say:

*'I get quite frustrated with him because it's always such hard work with him. Chris (TD child) and I would argue over everything ... trying to get through to him and trying to explain to him!! ... I would often say to him Chris your sister has autism you know, would you not just give her a break?!'*

Compounding the problem of age inappropriate expectations is the fact that children often respond in socially desirable ways to receive approval from and maintain a connection with important adults in their life, such as parents (Sahoo & Suar, 2010). This can manifest in the child taking on adult responsibilities – such as, self care incongruent with their age, care of the autistic sibling or psychological responsibilities like protecting the parents emotional wellbeing (Jurkovic, 1997). Elements representative of these documented findings were evident in various collected data across the current study. Of participant parents, 16 of 20 reported either consciously or unconsciously recruiting TD siblings into precocious caretaking roles - or inadvertently fostering and rewarding selfless behaviours exhibited by their young TD children that were incongruent with their age. In conjunction with this, and testimony to the bind which parents find themselves in, many parents simultaneously expressed concerns for their TD children regarding excessive *'people pleasing'*, as found by Sahoo & Suar (2010), related to their autistic sibling, the parent or distal others.

Additionally some parents communicated specific concerns with TD female siblings, namely, excessively *'mothering'* their autistic sibling. The term *'fathering'* was never used in relation to male TD siblings.

Parents also gave voice to their fear that their TD child *'has to grow up too quickly'*, missing out on some aspects of childhood because they were unavoidably exposed to, what parents felt were, adult situations and anxieties. This concern is not unfounded, as research shows that children who grow up too early may learn to ignore and neglect their own needs in doing so (Sahoo & Suar, 2010)

Though most participant parents expressed worries about the quality of childhood for their TD children, some were ambivalent about their child's inclination to care-take, and seemed unaware of the contradictions in what they said as previously mentioned. As an example of this one might consider the statement below. One mother, Marie, while speaking about requiring help from TD siblings in the household on stressful days, stated the following about her TD daughter:

*'She's a mammy ... She's a people pleaser ...she'll just get on with it ... when you need help you're going to go to the kid that is going to do it ... I worry about her ... she is a little bit of the Cinderella in the family ... she's allowed herself to be sucked in to being Micah's (ASD child) watcher ... I've said, Milly, you don't need to be the mum. I've got this. You can just be the sister ... and let me worry about the rest'.*

Marie asserted that her ten-year-old child had *'allowed'* herself to become *'watcher'* to her autistic sibling, firmly placing the outcome of this situation with the ten year old - while at once stating that this is the same child she goes to for help when things in the home feel unmanageable. She did not communicate any awareness that her statement was incongruous, or that her messages to her child were peppered with double binds, though her concern for her TD child was sincere and genuine. Marie was not alone in this incongruity.

Often parent accounts showed their struggle to keep a balance, evident in how they vacillated between discussing their anxieties about TD children's childhood and trying to reconcile that with meeting the family's practical needs. Several parent interviews saw them share statements like, *'I worry'* or *'I just don't want her growing up too quickly'*. Having stated that concern, frequently parents went on to manage said worry with an assertion such as *'But he's grand fending for himself'* [Claire] or, *'Kids are accepting ...*

*they don't know what they are missing and not missing'* [Hugh]. This double bind was apparent in various ways in the accounts of parents who participated.

Relevant to this is the issue how parents understand their child's self-care and caregiving behaviours. In examining the self reported experiences of children with an autistic sibling and the self reports of their parents, one study reported a significant finding, namely that parents and siblings defined the attributes 'helpfulness/responsibility' in an almost dichotomous manner (Barak-Levy et al., 2010: 155). In the current study, although some parents considered helpfulness and responsibility, to be positive attributes of the TD child, TD children's narratives showed that, for them, these same attributes could be a source of distress. Their dichotomous experiences became evident in interview when Claire's son, Christopher, demonstrated he was not '*grand*', as his mother Claire asserted, but instead was resentful that his parents, '*Have to be focusing on what she wants to eat and then it's like for me, it's 'fend for yourself whatever you can find, find'*'. Similarly in interview, Hugh's TD son said of helping at home, '*I have to help ... I have to ... it feels bad or like, bad because I have to do a lot more... like doing more chores ... I wouldn't feel good. I'd feel bad ... Like I might be late for training for football'*'. The TD sibling's appraisals of the experiences cited by their parents illustrated that self-care and caregiving were behaviours that children engaged in, yet had some negative feelings about. This was not unusual in the data and this is discussed further in the next chapter.

Parents often believed that their TD children were '*cool*' with certain events that happened in the home but TD children's accounts suggested that parents were sometimes mistaken. In the current study, in terms of physical space, parents reported that TD sibling's belongings, their bedrooms, and even their beds could be commandeered by their autistic sibling with impunity if that was what was required in the moment. As a study by Bagenholm and Gillberg (1991) found, TD siblings of children with autism reported their difficulty with their autistic sibling disturbing and breaking their belongings. Moreover, one participant mother, Nuala, described how her autistic child slept in a different TD sibling's bedroom each night saying, '*he snakes around and he sleeps on anybody's floor or anybody's bed'*'. Nuala reported her belief that this was something that the TD children in the home were '*cool*' with. In interview however, her six year-old daughter, Nell, described a tricky day at home as a day, '*When I want to be alone, I wanted to be alone but no-one letted (sic) me'*'. This statement suggested that there were times when the TD child would like space to be

alone but could not achieve it and she was not as ‘cool’ with this as her mother might believe.

Conversely, Kyle, aged 10, spoke of how had preserved some space for himself, not by looking for help from his parents, but by locking his bedroom door both during the day and night because,

*‘He (ASD child) just gets really annoying because he’s just taking my stuff. Taking and breaking them ... and then I come and try find it... they have it ... and I’m not able to get it back ... I have to sort it myself ... I don’t really know why, but usually I have to sort it myself.’*

Kyle’s inclination to ‘sort it’ himself suggests that self reliance in these situations had filtered into his thinking and coping despite his young age. Kyle’s parents, however, demonstrated a growing awareness that he was managing in this way. His mother, Kate, spoke of only recently realizing that her son found this annoying, and explained how she and her husband now actively try to engage him in conversation about how he is feeling to counter this. Kate observed, *‘He doesn’t share things with us ... he said he hadn’t told us because we had enough to worry about ... he is trying to minimise issues for us. He doesn’t want to be a problem’.*

Like Kyle above, existing research on TD siblings of children with chronic conditions finds that children in this situation often run the risk of abandoning their childhood to assume ‘*precocious responsibility*’ in relation to emotional caretaking for their family members, particularly parents (Bendrix & Siveberg, 2007: 414). Akhtar et al. (2012: 307), in their study of children with spinal injuries, characterize this as children who essentially attune to stresses faced by their parents, and then adopt a strong adult parental role towards the parent to manage this. Several children in this study echoed Kyle above and similarly reported managing worries, sadness, or physical altercations with their autistic sibling without reference to or support from a parent. One 10-year-old child, Eavan, disclosed that her older autistic sibling could sometimes hit her. In interview, the following exchange took place:

R: If you and Elizabeth have an argument how is that solved, how is it fixed?

E: *I don’t know (she thinks for a moment) ... I’d fix it. Yeah.*

R: You’d fix it. And would you ever go to mum?

E: *No ... because I’m used to it.*



Participant Emer, who was mother to Eavan, seemed aware of such issues in interview, and a needs must approach prevailed. Emer was not unique in reasoning that every interaction could not be monitored, asserting: *'Well you can't be fair, it's just - that just can't happen because our situation in the first place is just not fair'*.

Mudaly & Goddard (2001: 228) argue that in times of high stress parents can engage in certain processes by, *'informally and persuasively'* recruiting the child to their own needs. One participant in this study, Gloria, mother to four children and parenting alone, frequently talked about how she aligned her eldest child at home, her only daughter, six-year-old Gina, as her ally and helper in the household. Gloria spoke of wanting Gina to feel *'me and Mam are on the same team and we're doing this together'*. She stated her belief that this helped her daughter feel better on challenging days. Gloria explained:

*'... she takes on a role of a second mother to George and knows that she has to help out with him ... George is screaming I can hear her trying to say ... let's put our hands on our knees and quiet mouth ... there's other days she'll say, 'I'm going to take off George's pants because he had an accident'. She takes it in her stride, it's nothing to her. She's gotten used to it'*.

Even as she spoke Gloria sighed heavily, acknowledging that Gina's childhood was compromised and she added, *'that's just the way it is'*. Gloria's account suggested that her context ensured she could only ever make a choice of the necessary. Gloria's practical needs day to day trumped the concerns she expressed below, for the wellbeing of her daughter, Gina, because her autistic child's needs ensured that there were always other considerations that had to come first. Gloria's concerns for her daughter's childhood and wellbeing were manifold and she became emotional while expressing them as this final extract from her interview illustrates:

*'I just want her to be a little girl and not have this pressure on her ... She sees me getting overwhelmed and she knows when I'm stressed out and she tries to keep everything else calm in the house ... I just want her to enjoy being six ... I just don't want her growing up too quickly'*.

## **Conclusion**

This chapter focused on parent accounts of life and parenting TD siblings in a home where one child had a diagnosis of autism. The challenges and rewards for mothers and fathers related to caring for all of their children were emphasized in recollections. In every

account, parents expressed that there were many positives, and yet despite this parenting was complicated by the presence of the autistic child in the home. The conflict between the family's practical constraints and the TD sibling's emotional and physical needs emerged as the issue which caused participant parents most concern; a concern reportedly compounded by the fact that the TD child's experience of childhood and the parent child relationship was inevitably overshadowed by their sibling's autism and the dynamics this created within the family.

The adoption of adult roles by the TD child that can jettison their childhood beyond their reach, can undermine their psychological health and development throughout life, including identity development, personality and interpersonal relationships (Jurkovic, 1997). It can also obfuscate the TD sibling's own legitimate need for care while at the same time forgetting that they themselves can become '*burdened children*' (Chase, 1999), prepared to do all they can to stay connected with and protected by the parent.

The majority of parents in the current study reported that they saw this paradox, and considered it an inevitable consequence of the situation in which the family found themselves. Parents lamented the irony that saw aspects of their TD child's childhood sacrificed to the demands of their autistic sibling's needs, but did their utmost to manage this as best they could. Equally, all parents said that their desire was always to ameliorate the disruption of childhood for their TD child in any way possible. This reported disruption to childhood for typically developing children, and its effects on their relationship with the parent in this context, is the subject of the chapter that follows.

## CHAPTER SIX

### FAMILY LIFE IN THE CONTEXT OF ASD

#### CHILDHOOD INTERRUPTED

Chapter Five examined daily life in the home as reported primarily by parents of typically developing children who have a sibling diagnosed with autism. Parents acknowledged the practical and emotional hurdles that they negotiate every day while parenting, their worries about what they ‘get wrong’, their efforts to protect their children from the stresses inherent in their family context, and their desire to ensure that all of their children have a ‘*happy childhood*’ by protecting the parent child relationship, despite challenges. This chapter looks at these issues primarily from the TD children’s perspectives.

The theme of this chapter was inspired by a statement from one of the children who, in speaking of her life stated, ‘*It’s not easy. Well, on an easy day it’s actually quite stressful as well, sometimes he takes lots of attention*’. This statement echoed the sentiments of the majority of children who participated in the study. Interviewing such young children was both challenging and rewarding. Direct quotes from the children are used optimally and encapsulate the intensely ambivalent feelings TD children can encounter in loving a sibling whose condition has interrupted childhood as they knew it.

For children, the attachment relationship in childhood under optimal conditions can be protective for the child against poor developmental outcomes. The developmental view of the child proffered by attachment theorists underscores the central importance of primary relationships, that is, the requirement that the child’s needs be sensitively met by an attuned caregiver. This is fundamental to the child’s development of a self that is, self confident, self reliant and self regulating (Ainsworth et al., 2015; Bowlby, 1958, 1990). Bowlby (1990) uses the term ‘secure base’ to describe the child’s relationship with a sensitive attachment figure who responds appropriately to the child’s needs. For children, this is usually a parent, and this ‘secure base’ may become compromised for the TD child when they have an autistic sibling whose needs might obscure their own.

As noted previously, the psychological functioning of parents largely determines a child's social emotional development, as it is within the family that children primarily learn to manage relationships (Belsky, 1984; Eisenberg et al., 2006; O'Connor et al., 2007). Belsky (1984) notes that the personal psychological resources of parents, and contextual sources of stress and support, can each directly and indirectly affect parenting. In the current study, findings suggest that the risk for the child resides in the home context, as ASD generates unique stressors all family members. Belsky (1984: 83) further cites the psychological resources of parents as *the* most effective moderator of the parent child relationship in contexts where stressors are significant.

The participant children in the current study ranged in age from six to 12 years – a life stage that psychologists term 'middle childhood'. The notion that wellbeing for children is underpinned by bonds established early in life is well documented in developmental psychology literature and, more specifically, the relationship between parent and child is crucially important in middle childhood (Collins et al., 1995; Darling & Steinberg, 1993; MacCoby & Martin, 1983). Collins et al. (1995) assert that self esteem and competence for the child are particularly associated with parenting in middle childhood that is attentive and responsive to the child's needs. In the context of a home where one child has additional needs, the parents' personal psychological resources may become strained as they try to meet the conflicting needs of all their children.

This chapter explores this from the perspective of typically developing children, examining issues they gave voice to, such as their experience of life at home, their experience of differential parenting, their worries, and the strategies they employ to preserve their connection to their parents. The chapter firstly establishes the home environment and the emotional climate of that environment. It then focuses on the ways in which parenting is shaped for the TD sibling by these. Throughout, is an exploration of participant TD sibling's experiences of the parent-child relationship, which looks at TD children's reports of stress, coping, feelings of loss, and the emerging self-concept of the TD child in this context.

## The Typically Developing Sibling at Home

In the current study, the often-irreconcilable needs of the typically developing child and the autistic child created similar dilemmas for participant children, as it did for their parents, as the following section illustrates.

As Chan and Goh (2014) found in their research on families with autistic children, and as confirmed by the current study, parents' efforts to sensitively meet the needs of all children is frequently fraught with difficulty because it is unavoidably determined by a hierarchy of needs - shaped primarily by the needs of the autistic child. This can result, as TD sibling's narratives here indicate, in the parents' disproportionate prioritizing and care of the disabled child. One mother, Janice, acknowledged this and summed it as follows:

*'My child has ASD, and unfortunately it's that child that is the centre, the focal point. Nobody is educated around 'What about my other kids?' The other kids aren't the focus then are they? Because the other child is the one with the special needs ... sad isn't it?'*

Additionally, just as child participants in the study by Chan and Goh (2014) did, typically developing participant children in this study expressed that they were aware of this hierarchy, and the fact that that their connection with, and place in the parents' frame, often lost its potency because something else – namely the needs of their ASD sibling – were regularly more powerful. As Fionn, aged 10, explained: *'My Mam needs to spend more time with Fiachra to get him help, it doesn't bother me at all'*. Not all TD siblings were as magnanimous as Fionn, however. Several participant children bemoaned their relegation, while other expressed ambivalent feelings about it. Of participant TD children, 11 of 15 children reported that they made some associations between their siblings condition, what happened in the home, and what they experienced in their relationship with their parents; with many TD children citing their autistic sibling's overt behaviours as a frame of reference for their experiences.

On a practical level, many TD siblings' accounts showed they had resigned themselves to a childhood that was sometimes interrupted, believing both that *'Life is harder'* but also *'not hard other times'*. Having a sibling with a disability affects the lives of TD children. This can happen imperceptibly and also in larger, more significant ways. Similar to extant literature, the present study found that adjustments and limitations to life were ubiquitous for all participant families (Chan & Goh, 2014; McHale et al., 1984; Moyson & Roeyers, 2012; Quintero & McIntyre, 2010). While Chan and Goh (2014: 165) assert that TD

siblings *'are not victims'*, they acknowledge - as was found this present study - that there are certain adjustments that must be made, and by default limitations and additional responsibilities can be foisted on TD children in a home where one child has a diagnosis of ASD.

Children in the present study reported, as previous studies have found, that life at home, because of their sibling's autism, meant that some accommodations to the needs of the autistic child were unavoidable (Chan & Goh, 2014; McHale et al., 1984; Moyson & Roeyers, 2012; Quintero & McIntyre, 2010; Rossiter & Sharpe, 2001). Moyson and Roeyers (2012: 98) use the term *'barriers to doing'* to describe tangible effects on TD siblings which see them constrained because of their sibling's disability.

The TD siblings in the current study shared various examples of this. Family holidays, socializing, and extracurricular activities were each reported by participant TD children here as sometimes problematic because of their autistic sibling. Speaking of the family's upcoming summer holiday, Amy, aged 12, reported with some frustration, *'I wanted to go to Munich ... there's nothing really to do in Munich for Conor (ASD child) ... in Paris we can go like, cart him off to Disneyland ...'* Speaking of her life, Amy went on to add, *'I can't have my music on high ... I can't watch South Park any more ... I can't have my music on when he's going to bed'*. Another child, 12 year-old Christopher, complained of a social life dominated by the ASD support group that was the primary outlet for the family because, *'It kind of changed my way of life ... I go to all these parties with other kids or these meetings or these events'*. While the children accepted changes to life, Amy's list of what she 'can't' do, and her phrase *'cart him off'*, betrayed a degree of resentment for children that can result from such constraints.

Equally, it was reported that practical adjustments imposed on the family because of the autistic child's needs could affect ordinary daily routines at home and, by extension, what the TD child could and could not do independently. One mother, Denise, described how her home was on continuous lockdown where *'doors and windows are locked at all times'* because her ASD child was a flight risk. She added that her typically developing child, Elena, was constrained in that she could not do certain things even though she was capable of doing them. Denise reported that her TD child always needed to have a parent unlock doors for something as simple as using the bathroom or the kitchen because, as Denise explained:

*'John(ASD child) will go in and drink shampoo ... John will put metal in the microwave so everything is up high' ... we're on high alert the whole time ... always watching him ... it is like having a toddler with the speed and the strength of a 9 year old'.*

The caretaking responsibilities and maturity demands (Rossiter & Sharpe, 2001: 66) placed upon TD children, which can result in their engaging in activities they might not otherwise choose were replete in children's account in the present study. Participant parents also reported how TD siblings on occasion had little choice but to share responsibility with parents who were often under pressure. One parent for example explained how her eight year-old TD son assumed such responsibilities without complaint. Janice explained:

*'I'd like to maybe try not put such an adult role on him. He's used to being stressed at this stage now, so ... he tries to fix it. He'd be like, 'I know you're stressed- do you want to have a coffee, do you need to have a sleep, maybe take a half an hour mam in the bedroom ... and he'd mind her for me'.*

Alternatively, TD children spoke about not getting to do things that they reported as being important to them. In interview, 12 year-old Amy spoke passionately of her interest in music and of the piano lessons that she loved. She added that on the day of interview, a trip the doctor with her autistic sibling had put an end to her lesson. Amy did not complain or protest. She stated this as a matter of fact and seemed resigned to it: *'Today, well I was supposed to go today but I cant go cause he banged his head, I've to go to piano, so I normally go with her (mother)'.*

Moyson and Roeyers (2012: 98) additionally use the term *'barriers to being'* in relation to TD siblings and this became evident in findings here also. One child reported that for her, such barriers to being extended to something as ordinary as being unwell. Ten year-old Eavan reported that her 14 year-old autistic sibling had sensory issues and as a result Eavan could not cough when she had a head cold because it would result in an altercation with her autistic sibling. Eavan explained, *'Elisabeth hates the sound of coughing- it hurts her ears ... so she'd hit me if I cough and it's really hard when I have a cold.'* Eavan's mother, Emer, confirmed this and similar occurrences in her interview adding, *'I'd say she finds is hard ... most of the time the house revolves around Elisabeth ... as a child it's not normal that her older sister's needs should come before hers'.*

Although participant parents were not asked about their own childhood, during fieldwork, 13 of 20 parents referenced this in relation to home life what they expected of their TD children. Emer above felt somewhat at a loss to understand her TD child's complaints of unfairness related to her sibling because she herself had grown up as an only child. One father, Mark, spoke of the orderly home his mother had always maintained, and shared how the chaos in his own home and his expectations of his TD children filled him with anxiety, because he felt *'I'm a bit OCD, but I don't live in an OCD house'*. Two participants explained that they had grown up in army households and were used to orderly predictable homes. These parents said that this made them aware of being too regimented with their TD children, yet most parents felt that consistent structure and constraints were a necessity if stress was to be kept at a minimum. In a household that was reported as feeling chaotic by many TD children and parents, some semblance of orderliness was reported as desirable but difficult to achieve. In the main, TD children's accounts of home reiterated what parents shared, namely that childhood for them as young children, as one father, Derek, stated: *'it's just not the same, you can't just do what you want when you want, there are certain requirements you have to meet'*.

Echoing Quintero & McIntyre (2010: 37), Derek's assertion reiterates the rebalancing and restructuring which is a regular occurrence in the homes of autistic children, as parents try and sometimes fail to divide their time and meet the needs of typically developing siblings as well as the autistic child. One mother, Kate, summed up home life for her TD child as follows: *'At home it is the way it has always been ... volatile some days. Sometimes at home we know when we are trying to deal with things that it's not fair. It's all we can do but it's not fair'*. The unfairness that was reported as permeating the climate in the home was noted by all TD siblings who participated, and is discussed in the next section.

### ***The Typically Developing Sibling and the Emotional Climate at Home***

Without exception, the children's narratives demonstrated that family life - a primary developmental context for the children, according to Eisenburg et al. (2006), had been altered by the presence of their autistic sibling in the home. The majority of participant children reported experiencing life at home as being, as 10 year-old Ned said, *'fun but a lot of the time it would be hard'*.

As their parents had, child participants described the climate at home in terms of good days and tricky days – each determined by their autistic siblings' behaviour. Good days were



recalled by participant TD children as days when there were no meltdowns and the house was, as Kyle, aged 10, stated, *'peaceful, quiet, not like an earthquake!'*. Some children associated good days with exceptional events – two referenced Christmas time in talking about this issue, while Hope, aged eight, spoke of her First Communion, which she remembered as a *'good day'* because *'Henry didn't do anything wrong on that day'*. Their autistic sibling's behaviour was a frequent frame of reference used by children in their narratives. If their sibling was, *'in a good mood not like in a bad mood ... crying all the time'* being at home was experienced as, *'calm'*, *'fun,'* *'quiet'*, or *'a family day without anyone moaning'*. On these days, the children said that they could enjoy their parents' attention and maybe have some one to one time with a parent. Lily, aged six years, poignantly and simply described a good day at home as: *'When mammy plays with me ... and daddy reads me stories'*.

Reiterating existing research (Ferraioli & Harris, 2009; Griffith et al., 2010; Johnson & Rodriguez, 2013; O'Moore, 1978; Rodgers et al., 2012; Woodgate et al., 2008), difficult days at home were linked by TD children to autistic behaviours and described using descriptors very similar to those chosen by parents. Words and phrases included mentions such as such as *'crying'*, *'emotional'*, *'meltdowns'*, *'tantrums'*, *'screaming'*, *'can't sleep'*, *'shouting'*, *'hitting'* and *'stressful'*. As Ferraioli & Harris (2009) previously found, the participant TD children in this study processed and understood these experiences in age appropriate ways most of the time. There was, however, an additional dimension to difficult days at home reported by children in the present study. The emotional climate ensured that stress filtered into ordinary family interactions and crystallised in increased negative interactions between parent and TD child as Smith et al. (2010) confirm. Children's reports suggested that they were acutely aware of, and highly sensitive to, nuanced changes in how their parents responded to them once the parent became stressed as a result of a strained climate at home. The TD child's experience of this change could generate upset and confusion for the child. Six-year-old Gina who, as discussed earlier, was recruited by her mother as helper and ally, expressed this as follows:

*'If your brother is autistic ... sometimes they do go madness crazy ...sometimes when she's (mother) angry at me, I get a bit of a fright ... I just start crying because I get a bit frightened. She just tells me some things and sometimes it gets me confused, because sometimes she tells me to do something and then she tells me another thing.'*

Alternatively, a difficult day became the catalyst that caused the TD child to experience anxiety about the parent and this could activate caretaking behaviours, as eight-year-old Hope explained: *'Well, it's mostly my Mammy ... well, as I said it's stressful sometimes for my Mam ... it could get a little bit emotional. Then I might go over and give her a hug ...when she cries or something.'*

In order to meet their needs, a child's attachment behaviours are triggered by stressful situations (Ainsworth & Bell, 1970; Bowlby, 1958; 1990), such as those outlined above. As participant children's accounts here show, proximity seeking behaviours generated by stress, prompt the TD sibling to look to the parent as the 'secure base' outlined by Bowlby (1990). This need to connect with the parent was reported by the TD children in the current study as regularly eclipsed, coming second to the needs of their ASD sibling. On occasion, in a bid to stay connected to the parent, the TD sibling could begin to assume responsibility for meeting the emotional needs of the parent as Hope did. Alternatively, as Gina's account shows, the TD sibling could become confused about how to best respond to a parent in obvious distress and not know what to do for the best.

Essentially, participant TD siblings recounted their emotional and physical needs in the home as being fulfilled, but in an unreliable or inconsistent manner. When filtered through the lens of neurodiversity, it might be argued that we each have a way of being in the world and that the preceding statement is true of all families. Neurodiversity argues that variation across neurological development and functioning is a natural occurrence. Behaviour is particular to the individual. Parents spoke freely of the 'demands' of TD children also – and indeed of the own idiosyncrasies that caused them to be 'OCD' about the house as referenced earlier. Interestingly the behaviours of TD children were not framed as challenging by parents with the same frequency.

Depending on the emotional climate in the home on a given moment, the parent might respond sensitively and appropriately to the TD child's need, or the TD child's need might be, as one father, Ciarán, stated, put on *'the backburner'* to be dealt with *'at some stage'*. Several TD siblings recalled that they could never quite anticipate which outcome to expect, as eight-year-old Joe's articulation of his mother's behaviour illustrates: *'In the morning she can be very like annoyed, but sometimes it can be very good...she tries her hardest not to be annoyed, but she can still be annoyed sometimes'*. The TD sibling's reported experiences have a parallel in research, previously discussed by Meschling et al. (2018), who found that, in drug using parents, this kind of unpredictability was

commonplace and determined by the parents' drug use, where periods of active drug use often resulted in parenting that was inconsistent and arbitrary, which could result in ambiguous loss for the child.

Parents and TD siblings in the current study reported that, given the atmosphere at home, parenting could be equally arbitrary and, therefore, occasionally TD siblings wanted to escape to something a little more predictable and tranquil. They did this by visiting friends, sometimes for up to four hours at a time and then – *'coming back when everything is calm'*. One mother Janice gave a typical example of a visit to her mother's home with her eight year-old TD son Joe:

*'... you'll see him and he'll just want to stay in my mam's house ... last week he stayed there two nights ... he's like, 'Can I just stay here tonight and get a nights sleep?' and my mam is like, 'I'll just bring him to school, he's tired'. So I'll bring her (ASD child) home then'.*

It appeared from TD sibling's account that the climate in the home ensured that home was not always a refuge and place of safety. Despite good days, it could be a place that they wished to escape or take a break from regularly. Participant children in the current study often placed responsibility for what was happening in the home at the feet of parents who they often experienced as *'unfair'* and this is the focus of the next section.

### ***The Typically Developing Sibling and Parenting***

As previously noted, in families with children with disabilities, there is increased differential parenting - and the differentiation most often favours the child with the disability (Lobato et al., 1991; McHale and Pawletko, 1992). Children's accounts in the current study suggested that, from the TD child's perspective, the most discernible difference in parenting was the issue of parental attention to their emotional and physical needs. Every participant child mentioned this, and all spoke of this in similar ways. Parent accounts confirmed TD siblings' claims that differential parenting regularly took place for a variety of reasons linked to the autistic child's needs.

Due to stressful daily demands, attention paid to TD siblings was recounted by both child and parent participants as fragile and prone to change with little or no notice. Boyle et al. (2004) assert that, for the TD child, seeing their sibling cared for in ways that they themselves crave, may cause a child to feel diminished and unseen. Parents acknowledged this and reported feeling that this was regrettable but unavoidable. One father, Ciarán,

explained: *'We don't have enough energy to give him (TD child) the same attention level as we do for her (ASD child)'*. Another father, Derek reasoned that this was not deliberate and could occur quite subtly because: *'You can divert a lot of your attention to the kid with higher needs'*.

Ostensibly, TD siblings understood this and reported on it magnanimously. The language they used sometimes showed them identifying strongly with their parents, as ten year-old Kyle did. Kyle, who had two autistic siblings stated, *'It's more that I don't really get attention ... I'm ok with it really because I understand now that they have to keep their attention on them because it'sk crazy and all'*. Although research finds that children like Kyle, who understand why these differences in parenting are taking place, suffer less negative effects from differential parenting (Kowal et al., 1997; McHale et al., 2000), some accounts in the current study showed subtle indicators that there was a 'sting in the tail' of this kind of parenting for particular TD children.

Narratives showed that the intellectual mechanisms that allowed TD siblings understand differential parenting did not dilute the emotional responses that signalled their distress. Typically developing sibling's interviews demonstrated that a routine incident could loom large and leave the TD child feeling a little forgotten. While speaking of the night-time routine in the home and her parents' attention, ten year-old Milly stated, *'Sometimes like, they go in and check on him at night and then off back into the sitting room without coming to me'*. Similarly, although 10 year-old Eavan protested that, *'school is too long'*, something as innocuous as July provision for her autistic sibling was understood by the child as: *'Good things happen to her that don't happen to me ... like her July supervision ... she gets to go to fun places. I never go anywhere with my mum, never'*. Eavan's account implied that, in her mind, special school arrangements equalled more attention for her sibling. Eavan's attempts to remedy this may be the reason why, despite her being 10 years-old, her mother, Emer, reported that, *'She would sleep in my bed a lot ... I can see that she needs it. So, I will allow it a little bit.'*

There were also occasions when TD children did not slink away quietly but actively tried their utmost to secure some parental attention for themselves. One participant, Marie, mother to Milly above reported:

*'If he (ASD child) hit her she would take that moment and it would be high drama. It would be lots of noise and attention, that he hit her. And you'd be going, ok well'*

*Milly, that was an accident. He said sorry. And you're screaming like you need to go to the hospital.'*

Marie had some insight into her daughter's behaviour stating simply, '*She wants attention*', and given Milly's statement above, it seems that Marie was probably correct in her assertion. Dreikurs and Soltz (1990) argue that there four reasons why children misbehave: to get attention, to feel powerful, to make their parents feel inadequate or to exact revenge. Arguably, Milly's dramatic response to her altercation with her brother was indeed a bid for attention. Other parents reported how their TD children used school as a means of putting themselves centre stage by either acting out for teacher, or having difficulties with classmates. One father, Ciarán, explained his belief that such behaviours came from his TD son's anger at his parents and his desire to be seen by them:

*'... in school particularly ... he's got this thing that he wants to be the centre of attention and ... he wants everyone to look at him ... that means he does something bold ...he kicks someone ... but he gets caught ... Christopher is really not happy with anything we do at the moment'*.

Framed by Dreikurs and Soltz (1990) motivations for misbehaviour, it seems that, for Christopher, these behaviours serve to get his parents' attention, embarrass his parents, and may also give him a sense of power. Parents reported that these kinds of issues were quite manageable but, in each case, they required a period of time at home where the TD sibling became the immediate focus of both parents.

As discussed in Chapter Five, an examination of data saw parent assertions sometimes undermined by what their children had to say on the same issue. Equally, on occasion, when considering the parent and child narratives together, the typically developing child's ambivalence about their parent and/or the sibling became apparent in what the children did not say – and instead, triangulation with parent reporting often exposed issues that lay beneath participating children's overt statements. It appeared that for TD siblings, there were some unexpressed feelings underpinning what was said explicitly about the levels of parental attention they received. Kyle, aged 10 years-old has a younger sister and a younger brother, both with a diagnosis of autism. He explained sagely that: '*They are mostly taking up all the attention ... I'm ok with it really because I understand*'.

However, Kyle's mother, Kate, reported her experience of Kyle's anger about her lack of responsiveness when it came to her relationship with him:

*'He was sitting in the living room ... I was out dealing with something Kim was doing ... and he said 'I was shouting for you and I was being hurt by Karl ... You weren't listening to me'. And I said ... I didn't actually hear. But he said, 'Well you never hear!!' ... that was the anger behind it. And I said, 'I'm here now and I'm listening now'. And he said, 'Well it's fine, it's done now!!'.*

Kyle's angry admonishment, that his mother never hears him, suggests his sense of injustice regardless of his statement that he understands the lack of parental attention paid to him. Similarly, 12 year-old Christopher, when speaking of his parents' attention stated: *'If I went to mam or dad for something they'd say – 'in a minute'. But if my sister went it would be instant reaction. ... it's fair because she has her condition'*. Christopher's open assertion was that it was *'fair'* that his parents respond to him less readily than they do his sister. However, his mother, Claire, indicated that Christopher was often *'very mean'* to his sister, which could indicate that he actually feels the situation is not fair at all. Claire added: *'He is just mean to her the whole time ... it could be like getting back at her - feck you, you take all mum and dad's time - it could be that as well'*. Accounts in the current research indicated that children do indeed engage, in what Claire calls, *'getting back'*, at parents and autistic sibling in quite circuitous ways. This is explored later in this chapter where TD sibling's management of stress is discussed. The reason why children may do this is discussed in the next section, which explores ambiguous loss experienced by TD siblings, as recounted in interview.

### **The Typically Developing Sibling and Ambiguous Loss**

Often families in the present study touched upon the fact that ASD can be an invisible condition. In conversation about his autistic child one father, Niall, explained *'... it's easier to see a child with a disability when they're in a wheelchair'*. Researchers have explored this aspect of family experience (Moyson & Roeyers, 2012) and in the current study the notion of invisibility took on an additional facet for TD siblings. In addition to the loss of belongings, safety, and privacy, various TD siblings touched upon the fact that they too could feel invisible or unseen - and the loss of parental attention was key in this. The feeling of being invisible was reported by TD siblings in this study as happening in two ways - through their experience of the relationship with their autistic sibling and through their parents' lack of responsiveness to their needs.

Research indicates that siblings act as confidantes, playmates, teachers and caregivers for each other (Dunn, 2011; Howe & Rinaldi, 2004). Additionally, it is a relationship of mutual engagement and reciprocity which informs the emotional development, social skills and emerging self-concepts of the children involved (Macks & Reeve, 2007; Kaminsky & Dewey, 2001). Kaminsky and Dewey (2001: 406) particularly note that the lack of reciprocity, so typical of autistic conditions, ensures a dearth of intimate exchanges between siblings. In a busy household, children can normally turn to each other when parental attention is diverted to other concerns, but for participant TD children in the present study, it appeared that the lack of parental responsiveness was felt even more keenly because this was not possible for some. Ten year-old Kyle summed this up by saying, *'I have a brother and a sister and I've no one to talk to'*. His mother, Kate, confirmed this when she said in interview: *'He is very, very lonely in the household. You know, the five of us can go out together as a family but I am chasing one, Kevin is chasing the other, and Kyle is left to his own devices'*.

Speaking of their autistic sibling, several other TD children made observations such as, *'I do wish there was someone to play with'*, *'they are not as fussed about you'* or *'they don't wanna speak'*. When speaking about her dream house, one of seven year-old Elena's wishes was, *'If John could talk'*. John is Elena's autistic older brother. While drawing this into her picture, the interviewer drew a speech bubble for John. Elena enquired, *'Well, what is he gonna say?'* The conversation continued as outlined below:

R: I don't know... what do you think he'd say?

E: *I think he would say ... 'Do you wanna play?!'*

R: Would he? And what would you say?

E: *Yes!!! (She laughs)*

Although the loss of sibling reciprocity was something TD siblings spoke of, accounts suggest that the loss of parental attention was more of a concern for TD children as they spoke about this at far greater lengths. Typically developing siblings reported that various therapeutic appointments with the autistic child, time spent on caring for the autistic child and regular meltdowns by the autistic child, monopolized parental attention much of the time. Accounts show some TD children tried to share in the attention received by their autistic sibling. They did this by being helpful to the parent, for example, learning techniques to calm their autistic sibling and joining with the parent in managing these

situations. One mother, Gloria, described how during her autistic child's meltdowns, her six year-old TD daughter, Gina, stands by her side instructing her sibling: *'You need to calm down, let's go on your ball, let's put our hands on our knees and quiet mouth.'* This suggests that, for six year-old Gina, being a helper is a way to address her loss, as it is preferable to being unseen.

Seminal research by developmental psychologist, Edward Tronick (1978), which has come to be known as *'The Still Face Experiment'*, may shed light on why many of the other participant TD children did not behave as Gina did but instead became stressed and abandoned their bids for parental attention. In their research, Tronick et al. (1978) show that after three minutes with a physically present but unresponsive parent, an infant will firstly engage in intense attempts to involve the parent – as Milly did when her autistic brother hit her as discussed earlier – and will subsequently move to distress and negative behaviours, as Christopher did in school, also discussed earlier.

Accounts in the current study suggested that TD siblings had become accustomed to the fact that their emotional and physical needs were met inconsistently by their parents. They reported that, at certain times, they accepted the momentary loss of the parent and they distracted themselves to manage this. As children with more agency than the infants studied by Tronick et al. (1978), several TD siblings in the present study reported choosing to withdraw from the family and engage in various self soothing activities to distance themselves from the stress they were feeling. This was very evident in older TD sibling accounts:

*'I play a bit of Minecraft or something to get my mind off it'* [Kyle 10]

*'I go into my room and I start reading'* [Milly 10]

*'I just go upstairs and listen to my music.'* [Amy 12]

In addition to such experiences, Elena, aged seven, expressed feelings about her mother's availability and responsiveness in a very specific way as follows;

E: *'When I get lost that worries me ... in the shops - well, I was looking at something and then my mam went somewhere else ... But you always find them, don't you?'*

R: Yes, you do always find them

E: *Just, some people don't find their mam*



Elena's belief that *'some people don't find their mam'*, may be an unconscious reference to her very real fear that when she looks for her, the parent cannot be relied upon to be there. Threats to the availability of an attachment figure can produce fear, anger, and sadness for the child (Ainsworth et al., 2015; Bowlby, 1990), as does the actual physical presence but psychological unavailability of the parent, as is proven by the Still Face Experiment (Tronick et al., 1978) discussed above.

Therefore, TD sibling's narratives suggested that the participant children in this study suffered a degree of Ambiguous Loss (Boss, 2000) in relation to the parent child relationship, created by their context as discussed previously. Of 15 participant children, 11 were older than their autistic sibling and had experienced parenting 'pre-autism'. Oftentimes, for the child, the parent though still physically present was now periodically psychologically absent and this resulted in grief and loss evident in children's accounts here. That fact that children themselves are grieving a loss just as their parents are, was acknowledged by only one parent, Kate, who ventured, *'He's probably in his own stages of grief as well'*. Certainly, interviews with all participant TD siblings in the current study demonstrated that the established fact of life for them was that they were dealing with a 'double' loss - their autistic sibling *'doesn't really interact'* and their parents were *'busy with'* their autistic sibling. The child's anticipation of the parents' attention or time could be thwarted in an instant. The fear and stress that results from this loss, cited by Ainsworth et al. (2015) and Bowlby (1990) can manifest in various ways, which are discussed in the next section.

### **The Typically Developing Sibling and Stress**

In the context of a home where one of the children is autistic, TD children's narratives reiterated parent accounts and showed that despite some measure of resilience, stress levels for all family members – including TD children, often ran high. A chronic condition such as ASD, and the daily interventions generated by these conditions, creates stressors specific to the lives of TD children living in this context. Vermaes et al. (2012) conclude that there is a small negative effect for TD children who have a sibling with a condition such as autism, and find that stressors in this context are associated with fear, depression, anger, and jealousy for children. Furthermore, additional research reiterates Vermaes et al. (2012) and reveals that there are a number of experiences and feelings that are common to

children who have a sibling with additional needs, namely: stress, worry, resentment, and a sense of needing to be more 'independent' (Meyer & Vadasy, 2007). Conversations with children in the present study reflected the negative effects cited above given that, as their parents had, participant children here used the word '*stressed*' frequently when describing their experience of life at home on an average day.

Many of the children in the current study demonstrated some level of agency in and understanding of their situation in an age appropriate way (Chan & Goh, 2014; Ferraioli & Harris, 2009). The parents of Joe (8) and David (10) each reported that autism and its effects was an ongoing discussion in their home. Ostensibly, these children demonstrated an almost unconditional acceptance of their sibling's autism. Eight-year-old Joe believed: '*Like it's not their fault that they get autism*'. Joe's use of the phrase '*get autism*' indicates the parameters of his understanding and illustrates what Bibace & Walsh (1980) found namely, the conflation by young children of illness and disability that sees them assuming the presence of some kind of contagion. In addition, the children's comments confirm Rubovits & Siegal's (1994) findings, that a naïve or limited understanding of chronic conditions can protect younger children from the full implications of the condition for a family. As a result, they perceive their sibling's condition as less worrying and so may experience less stress.

Despite this, as conversations progressed, it became clear that although some children's understanding of the effects of autism was limited, many of the children were nevertheless quite stressed. This became evident in that, their accounts showed that at times, they coped by engaging, in what Ross and Cuskelly (2006: 82) call '*wishful thinking*', a mechanism cited by the authors as the primary coping mechanism adopted by TD children in stressful home situations such as those dominated by autism.

Despite her comment '*it's okay if your brother gets autism*', when asked about her house of hopes and dreams, six-year-old Gina said she would change her home so that there would be '*No more madness, no more monkey madness for me*'. Gina defined '*monkey madness*' as '*When mum is mad and George goes crazy sometimes*'. This kind of escapism via wishful thinking was not exclusive to younger participants. Some older children referenced how they liked to spend time out of the home with friends and daydreamed of having a home like their friends. Friends' homes were perceived as '*good*' or places where there is a '*normal family*', the implication being that home life for participant TD children was experienced as abnormal. Christopher, aged 12, mused in interview,

*'... most of what I think is, I wonder what this would be like if she didn't (have autism) ... I wonder what it would be like, because I don't really know ... You see in movies or even with other people's houses ... they all sit at the table together ... and the two siblings ... the brother and sister bonding all the time ... dad he'd be doing stuff in the garden ... and the mam she'd be cooking at lot more ... completely normal ... it's difficult to live with sometimes'.*

Parents can underestimate complexities in the experiences of children who have a sibling with a disability (Sharpe & Rossiter, 2002) and, in some cases, they may unwittingly engage in behaviours that exacerbate stress for the child. Barak-Levy et al. (2010) find, as was found in this current study, that parents raising children who have an autistic sibling prize qualities such as helpfulness and responsibility in their TD children. Given that children often respond in socially desirable ways to receive approval from and maintain a connection to parents (Sahoo & Suar, 2010), it appeared that some of the TD children in the present study ultimately engaged in helpful and responsible behaviours, even when they found them stressful. Arguably, they did this without complaint because their home context exerted a subtle pressure on them to behave this way.

The TD children's accounts suggested that the context of the home had the potential to ensure that a perfect storm brews; namely, many participant children in the present study perceived their parents as overburdened, as Vermaes et al. (2012) have found. As a result, they attempted to contribute to the overall welfare of the family by sometimes suppressing their own needs, believing their parents time and emotional resources were already overloaded. The precocious responsibility that can develop for TD siblings in this context – as outlined by Benderix and Siveberg (2007) – can then lock the child into the behaviours prized by the parent (Barak-Levy et al., 2010). As a result, the TD sibling 'helpfully' prioritizes the needs of their parent and sibling above their own needs. Like parents, the TD sibling is then left with no avenue but a choice of the necessary. Narratives in the present study suggested that TD children frequently prioritise the parent, do what the parent needs them to do and say *'I don't mind'*. One ten year old boy, Fionn, when asked about his house of hopes and dreams, made a wish for his autistic sibling, and a wish for his parents, with no wish for himself. The same child mentioned more than once in interview: *'My Mam would tell me I'm her best friend. Yeah and I'm the best boy in the world. That's usually what she says'*.

Being *'the best boy in the world'* may come at a price for the TD child. Like Fionn, many TD sibling accounts suggested that it was important to them to be perceived by their parents as *'good'*. The problem with being *'the good child'* however, lies in the child being

too good and then living with the stress that this generates. The good child exists at the expense of the self (Chase, 1999; Jurkovic, 1997; Sahoo & Suar, 2010; West & Keller, 1991) and this kind of behaviour is far more likely to manifest when the child is insecurely attached to the parent (Byng-Hall, 2002). Insecure attachment to the parent is likely to occur where responses to the child are unpredictable and inconsistent (Bowlby, 1990) and as TD sibling accounts in the present study have shown, this can happen in this context. As a result, there is the risk of a maladaptive ‘loop’ of interaction being established between parent and the TD child that generates stress for the child.

The good TD child may be too compliant, too self reliant, too perfect, helps too much, grows up too quickly, and may ask too little for the self. The good child runs the risk of doing what must be done and pretending it is what they want to do – and by doing so, eventually disconnecting completely from their true feelings and real self (Jurkovic, 1997). In this study, TD sibling narratives implied that often they do ‘*mind*’ but they are not consciously aware that they feel this way or they feel they should not express this. The stress caused by this and the ways in which it is managed by the child is discussed in the next section.

### ***Typically Developing Sibling, Stress and Defense Mechanisms***

In their meta analysis of the psychological functioning of siblings, Vermaes et al. (2012) argue that TD siblings, in the context of chronic conditions, can perceive their parents as overburdened and as a result, they can suppress their needs believing their parents stress about their autistic sibling is enough for them to cope with. Alternatively, as suggested by children’s accounts here, stress and worry can become issues that the TD child manages alone because experience may have taught them that asking for a parent’s help is not particularly effective given that, as one mother, Janice, said of TD children, ‘*The other kids aren’t the focus.*’

The threat of disconnection from a caregiver - such as might present when an autistic siblings needs eclipse the TD child’s needs - generates significant fear and stress for a child (Ainsworth et al., 2015; Bowlby, 1990). The TD sibling accounts in the present study suggested that that they remained connected to the parent and protected from some harsh realities as often as they could by engaging in self-protective behaviour that took the form of defense mechanisms that operated to alleviate stress. This is suggested by the fact that their statements were often incongruous. For example, Fionn, aged 10 years-old,

demonstrated a degree of denial about how he felt. Speaking about a recent family outing with his autistic sibling, he recalled, '*Well, I had fun - we went to the zoo at night to see- there's like lights on and Fiachra was crying the whole way through. It wasn't a very good day*'.

Typically developing sibling's accounts showed that the children regularly used various defense mechanisms such as the incongruous statement above to dissipate stress while at the same time guarding against disrupting their connection to the parent. Defense mechanisms are adaptive and affect various measures of wellbeing. They serve to preserve the ego and relieve stress and anxiety, and they occur outside of awareness (Cramer, 2015: 114). An examination of TD sibling narratives here suggests that their use of defense mechanisms ensured that TD children who felt stressed, disappointed, or angry could escape those feelings at times when the feelings threatened to overwhelm them, or threatened to rupture the attachment to the parent. Defense mechanisms also operated in the realm of precocious caretaking (Bendrix & Siveberg, 2007), in that they protected the parent from the child's distress.

The use of defense mechanisms has a developmental arc. Very young children, usually up to age seven years, use denial as their primary defense mechanism and this manifests as: statements of negation, denial of reality, overly maximizing the positive or minimizing the negative, and displays of goodness and positivity (Cramer 2015: 115). TD siblings in the current study exhibited the subconscious use of such strategies, as confirmed by Fionn's statement above. Fionn was not unique. In interview, most children balanced expressions of what they found difficult with statements of negation or minimizing the negative. This was evident as they tended to qualify statements about unfairness or stress by often adding phrases such as '*it doesn't bother me at all*', or '*I'm ok with it really*'.

As children grow older, denial dissipates and is replaced by projection that sees children engage in behaviours such as, attributing hostile qualities to other people, or concerns about external threats such as, death, injury or assault (Cramer, 2015: 115). This too was evident in the current study. There were accounts from parents that suggested that their TD child's fears and stress had become generalized to issues beyond the home. One mother, Emer, spoke of her TD child's anxieties and shared the following about her 10 year-old daughter, Eavan:

*'I'd say in the last six months we probably haven't done much together ... she (Eavan) is very anxious, I remember her saying, ... what if there is a burglar ... what if one of the planes fall on the house. And, you know, what if, what if, what if ... '.*

Another father, Niall, spoke of how his son, Ned, aged 10 years-old manifests similar stress by obsessing about plans in an effort to assuage his feeling that something will go wrong. Niall went on to explain:

*'Ned can be anxious ... if he has got a school thing like this week, there would be days prep before it ... he'd have to keep on coming down to talk about what's happening on the day ... I'd say he has his worries ... there is always something, sort of feeding away at him'.*

By adolescence, children's primary defense mechanism is identification (Cramer, 2015: 115) and this too was evident in the narrative of TD children in the current study, even with younger children. Hope, who is eight years-old, identified strongly with her parents, aligned herself with them and said quite earnestly in interview, *'I feel ok because he does need a lot of attention... we need him to learn'*. Similarly, seven year-old Elena shared that she did not mind her brother's autism-dog in the home because, *'Well its cause, it should help him to talk'*. Both children simultaneously spoke of being angry with and stressed by their autistic sibling.

The use of these strategies, evident in TD children's accounts, seemed to operate as a safety valve, copper fastening a 'truth' for the child that was easier to live with. Some narratives indicated that the full dawning of challenges faced by the family was potentially too much for TD children to bear. Moreover, TD children at various times were reported by participant parents as additionally using regression – two older children were bed wetting, or suppression - Eavan (10) said *'getting up in the mornings is hard and I don't like homework'* - at the same time her autistic sister was off school indefinitely and her account suggested that she resented this.

The stress that triggered defense mechanisms was often linked to a specific worry for TD children. Negating statements (in heavy print below) frequently preceded or followed what the child said. As previously discussed, the 10 youngest participants were interviewed using the Three Houses Tool (Weld & Greening, 2003) outlined in Chapter Three. Given a choice of which house they would like to draw and discuss first, six of the 10 children chose to start with the 'House of Worries', one chose the 'House of Good', things while the three youngest participants chose the 'House of Dreams'. One child re-drew her 'worry' house stating, *'This house is too small'*, suggesting her feeling that a bigger house

was required to accommodate her anxieties. The fact that six TD siblings chose to discuss their worries first infers that worry was their most immediate concern.

The issues TD siblings reported worrying about often seemed incongruous with their age. Four children, one as young as seven, referenced their awareness that money was a concern for the family, and all children expressed anxiety about their parents and/or their autistic sibling. Narratives showed that children tried to minimize certain concerns to protect the parents' wellbeing as previously discussed (Chase, 1999; Jurkovic, 1997; Sahoo & Suar, 2010; West & Keller, 1991) so often they reported worrying alone. These behaviours were confirmed by parents' accounts also. The TD sibling's reports implied their attempts to be 'good', identifying as they did with adult concerns or minimizing their worries. Accounts suggest that this gave TD siblings some sense of agency in a situation largely out of their control. In talking about their family life at home, TD siblings referenced worries about issues that included:

The autistic sibling:

*'Sometimes I worry about my sister when she's like doing stuff, that she is near stuff that she's not supposed to be near ... Like she seems fine, she's only a slow learner. Like she's just normal like everybody else,'* [Joe 8]

Money:

*'Sometimes my Mam and Dad are short of money because we have special horse riding ... and sometimes, like very rarely, some speech therapists. It costs over €300 ... money isn't as important as other things in life.'* [Fionn 10]

Parents:

*'Well, there's nothing really to worry about with my Dad ... when we were at this autism thing for Henry my Dad was crying ... that's actually the first time I saw him cry'* [Hope 8]

Additionally, there were children who managed their worries without looking to the parent for support. When 12 year-old Amy spoke about her relationship with her mother she described it as, *'Okay, fine ... almost perfect'*. Moments later, when asked who she looks to for support when she feels stressed, Amy replied, *'I wouldn't really go to anybody ... not really at home - I just don't really feel like I should ... like, its not really a concern to tell somebody at home. I can just tell my friends'*. Amy's reluctance to share her worries with her mother may have been her attempt to preserve their perfect relationship.

Defense mechanisms were used less when children were presented with a hypothetical situation. As discussed in Chapter Three, researchers advocate the use of vignette in interviewing children as a method that provides a less personal and therefore less threatening way of exploring sensitive topics (Kandemir & Budd, 2018; Barter & Renold, 2000). In the current study, talking in the third person, the use of a vignette gave a glimpse of a different dimension to the interior emotional lives of some of the older TD siblings. For example, 12 year-old Amy, above, had said that her life was affected by autism ‘*a little bit*’. Later in conversation, when the vignette scenario described in Chapter Three was introduced, Amy rolled her eyes and adopted an irritated tone of voice and said the following,

*‘Her brother would probably take over the house ... she’ll become really stressed ... if you go on holiday, you can’t really do anything - you can’t really go anywhere you really wanna go ... she’d have to go to a birthday party with all these little kids and play with them ... and mind them’.*

When asked what she could do to help her friend in that situation, Amy replied, ‘*Emm, I don’t know*’. Additionally, in this exchange Amy did not qualify any of her statements.

Typically developing children’s accounts suggested that, in an effort to be ‘good’, the children were very disinclined to overtly express their negative feeling without equivocation. Such feelings were expressed indirectly as previously discussed, and many accounts demonstrated that the children had little conscious awareness of how they felt. This was evident in what parents had to say about children’s covert resentments, of both the parent and their autistic sibling, that became obvious in particular interactions - what participant mother, Claire, earlier called ‘*getting back*’ at the autistic sibling and parent.

Resentment, as identified by Meyer & Vadasy (2007) and other negative feelings associated with stress as delineated by Vermaes et al. (2012) were referenced obliquely by the majority of participant children, who as ‘good’ children, did not openly express jealousy of their autistic sibling. Accounts of TD children’s resentment were however clearly identified by their parents. In what Punch (2008: 335) calls ‘*sibling’s backstage behaviours*’, some parents in the current study reported furtive behaviours by their TD child, directed at their autistic sibling, which could be unkind or outright aggressive. Parents reported that the TD child sublimated such behaviours into ‘*play*’ or harmless ‘*fun*’. One mother, Emer, communicated the following kind of incident that occurs



regularly between her 10 year-old TD child, Eavan, and her 14 year-old autistic sister, Elisabeth:

*'I find she winds up her sister at times and because Elisabeth is really clueless and naive Eavan can sometimes outwit her ... she might say to her, Elisabeth, if you could do that for me, I will do this. And then there is a trap further down the line. And it's a tricky one because I say to her, you know it's not fair to do that to your sister because you know she is going to fall for it'.*

Similarly, in speaking of her TD son, Claire explained that while her son claims he is playing with his autistic sister, his behaviour during their swimming outings suggest something more hostile:

*'It seems to be that's the way with him you know and he'll go swimming and I hate sometimes going swimming with him because we will go swimming ... and he will spend half the time dunking, or trying to drown Carly. He just won't leave her alone'.*

The youngest children who participated coped with their stress differently. In the main, their recollections showed that they did not conceal or obfuscate their feelings. They were not concerned with what behaviours might be socially acceptable and they vented what they felt unselfconsciously:

*'Sometimes I get a bit angry and I can't really control it that much. Because I just get too mad ... so sometimes I can slap him (ASD child) because it really makes me angry'. [Gina 6]*

*'When John pees ... He pees on the floor sometimes ... it makes me feel gross ... I just don't like him' [Elena 7]*

Although he had expressed some worries about his autistic sister, eight year-old Joe seemed to experience no resentment at all. While placing his sister in his House of Good Things he stated, *'Because well, Jill ... I'd say if she was not autistic she'd be asking for a go on my computer and all that. And that could be annoying'.*

Many parents, 16 of 20 interviewed, were aware of these kinds of behaviours and why their TD children engaged in them. The majority of parents recounted how they encourage their TD children to share stress and worries - and how they reassure TD children that, as parents, they do not need to be protected. One parent, Kate, rationalised her TD son's withholding of how he feels as follows, *'He doesn't want to be a problem because he probably feels when they take up a lot of time and energy and they're a problem ... you know'.*

Findings from TD siblings suggested that defence mechanisms allowed the child some agency in circuitously contributing to the family – protecting as they did the family unit and the self. Behaviours such as those discussed here functioned largely to preserve the child’s sense of self as a ‘good’ child rather than a self who was a ‘problem’ for the parent. The TD sibling’s emerging sense of self is discussed further in the next section.

### **The Typically Developing Sibling and Self Concept**

Rogers (2004) contends that self-concept is an overarching psychological construct that includes self-esteem, self-worth, self-image, ideal self, social self and personal traits and qualities. Further, Berk (2007) asserts that the ways in which self concept is influenced is debated and the general consensus is that both nature and nurture contribute to how a child understands and experiences the self. Although self concept develops over a lifespan, it is most malleable in the early years of a child’s development, so sensitive, supportive adults that surround the child are crucial to emotional health, particularly in middle childhood years (Oberle et al., 2014). Given that Berk (2007) adds that self concept informs interpersonal communication, because we react congruent with our beliefs about who we are and our beliefs about who others perceive us to be – it is likely that the parent-TD child interactions are informed by the TD child’s self-concept.

In the current study, participating children were asked to use three words that they believed their parents would use to describe them. This question was asked to establish a small window into how children saw themselves. While some of the youngest children used categorical terms to describe their parents - such as six year old Nell who answered ‘*My mammy has curly red hair. She has blue eyes*’, none of the children used these categorical terms to describe the self. When asked how their parents might describe them, two children answered ‘*I don’t know*’, two gave negative descriptors of themselves, and the remaining 11 children used positive descriptors indicating that they believed their parents saw them as variously, ‘*unique*’, ‘*kind*’, ‘*creative*’, ‘*the best boy*’, ‘*energetic*’, ‘*fun*’ and ‘*good*’.

When discussing interpersonal communication in the home, discussions about conflict and resolution furnished further interesting insights into how TD siblings saw themselves. Several participant children’s accounts indicated that they were cognisant of the link between conflict at home and their sibling’s autistic behaviours, and therefore these TD children largely attributed family disagreements or their parents’ mood to, ‘*all the stress on a little house*’. However, there were exceptions. One older TD child’s interview

demonstrated that he made only tentative links, partially attributing ‘trouble’ at home to his own behaviour. This child explained,

*‘You can cause more trouble than you realise, before you do something and it wouldn’t be you causing trouble ... if you do something now it’s kind of causing trouble ... she (mum) would say to me sometimes ‘you are causing these problems’.’*  
[Christopher 12]

The pernicious effects of chronic stress on everyone in the family also became apparent in an exchange with one very young participant. Six year-old Lily had spoken about her brother’s behaviours, and later shared that ‘*mummy and daddy are sad and crying*’. She went on to talk about her autistic brother and parents: ‘*Leo (ASD child) - sometimes he’s nice to me and plays with me ... sometimes hits me and calls me bad words. And sometimes my mam and dad shout at me*’. When considering why this might be happening, Lily attributed episodes of discord at home, solely to own behaviour, ‘*Because I don’t do the things they say, I don’t brush my teeth when they said it.*’

Lily then asserted that the three words that ‘daddy’ would use to describe her were ‘*Lily he’s bold!*’ Christopher similarly believed that his parents would describe him as ‘*annoying*’ and ‘*trouble*’. Both Lily and Christopher’s belief that somehow the challenges in the home were because of them, were striking. If the TD child’s internal working model of self is the self as ‘*trouble*’ or ‘*bold*’, this negative self concept, going forward into adolescence, can lead to unnecessary defensiveness, self sabotaging thinking, struggles forming close relationships and difficulties addressing personal wants and needs (Bowlby, 1990; Sroufe, 2005)

Despite living with varying degrees of daily stress, many of the TD siblings in the current study used positive descriptors when describing the self, as previously outlined. It appeared that, notwithstanding their accounts of difficulties at home, many of the TD children seemed what Pilowsky et al. (2004: 863) call, ‘*surprisingly well adjusted*’. This finding echoes existing research that finds no significant differences between the adjustment of children with typically developing siblings and those who have a sibling diagnosed with ASD (Bayat, 2007; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; McHale et al., 1986; Pilowsky et al., 2004). There are some existing findings, together with findings in the current study, that might explain why some participant children were able to preserve their positive self-concept while others did not.

Macks & Reeve (2007) contend that children with an autistic sibling report having a more positive self-concept, when particular contextual variables exist for the child that bolster resilience and limit risk factors. Among these, social support, larger families, and being older than the autistic child may each serve as protective for the TD child.

In the present study, all participant TD children were involved with ASD support groups and eight families reported regular involvement with and support from extended family, including grandparents – this ensured good levels of information and formal/informal social support which research finds can be protective for families and by default TD children (Schopler and Mesibov, 1984). Furthermore, eleven participant TD children were older than their autistic sibling and six had siblings other than their autistic sibling. Hastings (2003) argues that for older TD children there is an established attachment relationship with the parent pre-autism and this may be protective for the TD sibling in the long term. Similarly related to attachment, in addition to their primary caregiver, children form attachments to significant others. Seibert & Kerns (2009) find that children will redirect secure base attachment behaviours towards siblings when a parent is unavailable – in the current study, six of the TD children had other TD siblings that might act as surrogate attachment figure in this way. Moreover, Kaminsky and Dewey (2002: 225) reiterate Macks & Reeve (2007) finding that *'large family size appears to facilitate healthy adjustment siblings of children with autism'*. These findings may account in some part for various findings in the present study.

## **Conclusion**

Chapter Five saw parents reveal the daily challenges and positives in the home generated by having an autistic child in the family. Typically developing sibling accounts in the current chapter reiterate much of what parents reported experiencing. Although many participant TD siblings identified somewhat with their parents and claimed an understanding of and resignation to the family's circumstances, the majority – 14 of 15 in total – made reference to some extent of their frustration that life could be difficult because of their autistic sibling.

Findings in the present study confirm that TD children are not spectators in the family dealing with autism, despite the fact that they are often considered, such as discussed in

Chapter Four, which looked at when and how disclosure of their sibling's diagnosis is imparted to them. Many participating children demonstrated good relational intelligence and exhibited a clear awareness of the hierarchy, which operates in the home to prioritise the needs of their autistic sibling. As findings in Chapter Five and the current chapter illustrate, in the main, the experiences of TD siblings were mired in the needs of the parents and the family unit, so that how they cope may be a matter of necessity rather than choice. The majority of children reported finding life stressful at times though many added that they could understand why this was and believed they could cope.

The resilience of TD siblings was evident in that the 'super parenting' exhibited by their parents in the findings of Chapter Five was matched by TD children in their efforts to negotiate their situation positively, by being 'super children', managing stress in ways that would not burden their family. As young children often excluded from certain information and input related to family decisions as previously discussed, being a 'good' child was the primary way that children reported being proactive in a family situation that felt largely out of their control.

For TD siblings, their context rendered their developmental needs and their person invisible on occasion, as autism could overshadow many aspects of the relationship with their parents. The significant ambiguous loss that TD children grieve in this context was striking. It could be argued as a greater loss than that of their parents given that, in many respects, they have lost a sibling and aspects of the parent to autism. Accounts suggest that TD siblings often tried to counter this by actively trying to create moments of intimacy with the parent – as parents previously reported doing in Chapter Five.

Accounts from participant children see them straddling several polarities. Chapter Four clearly demonstrated parents' perceptions of TD siblings as children in need of protection, and the parents' reported exclusion of the TD child around matters related to their sibling's autism diagnosis suggested their efforts to confer said protection. Jarring with this were accounts from parents in Chapter Five, which showed how the pressures of everyday family life saw them vacillate between their desire to protect the TD child and their need for the child to engage in family life in a more adult fashion when necessary. When considering TD sibling and parent accounts together, it seemed that they were to be, at once: responsible yet powerless, autonomous yet obedient, innocent yet knowing, a child yet more than a child. Despite this, none of the participant children embraced a 'victim'

status. Each displayed tenacious agency in their endeavours to manage challenges while protecting their connection to the parent and supporting the family unit.

The next chapter presents a discussion and a conclusion about the experiences of TD siblings and the parent-TD child relationship, discussing the implications of findings for policy and practice.



Lily Aged 6 – House of Good Things

Good things for Lily included daddy reading stories, mammy playing with her and 'twistable' sweets.



Joe Aged 8 - House of Good Things

Joe was protective of his younger sister Jill and placed her first in his house of good things



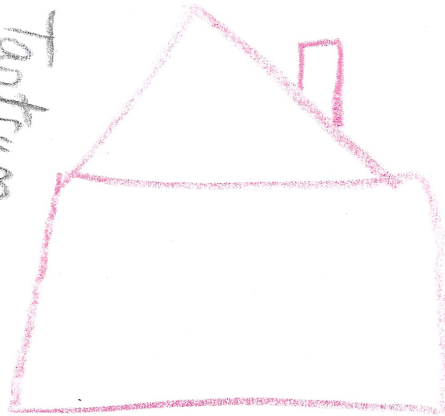
Hilly (8)

Hilly Aged 8 first drew the house above to represent her House of Worries. She immediately decided that this house was 'too small', turned the page over and drew the house below,

WORRY

sad

Tantrum



hard

not easy

stressful

Hilly (8)

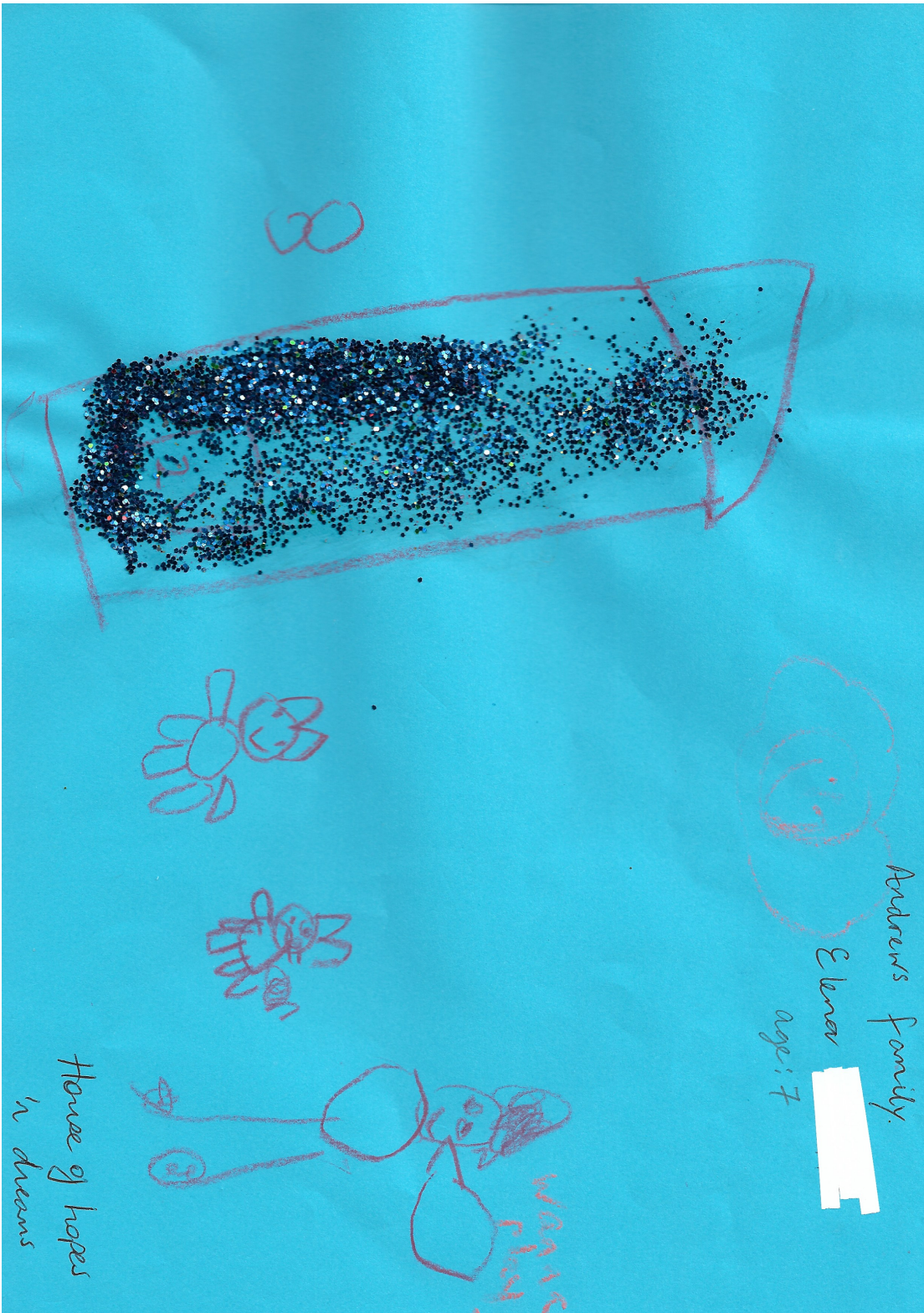
Hilly Aged 8 – House of Worries





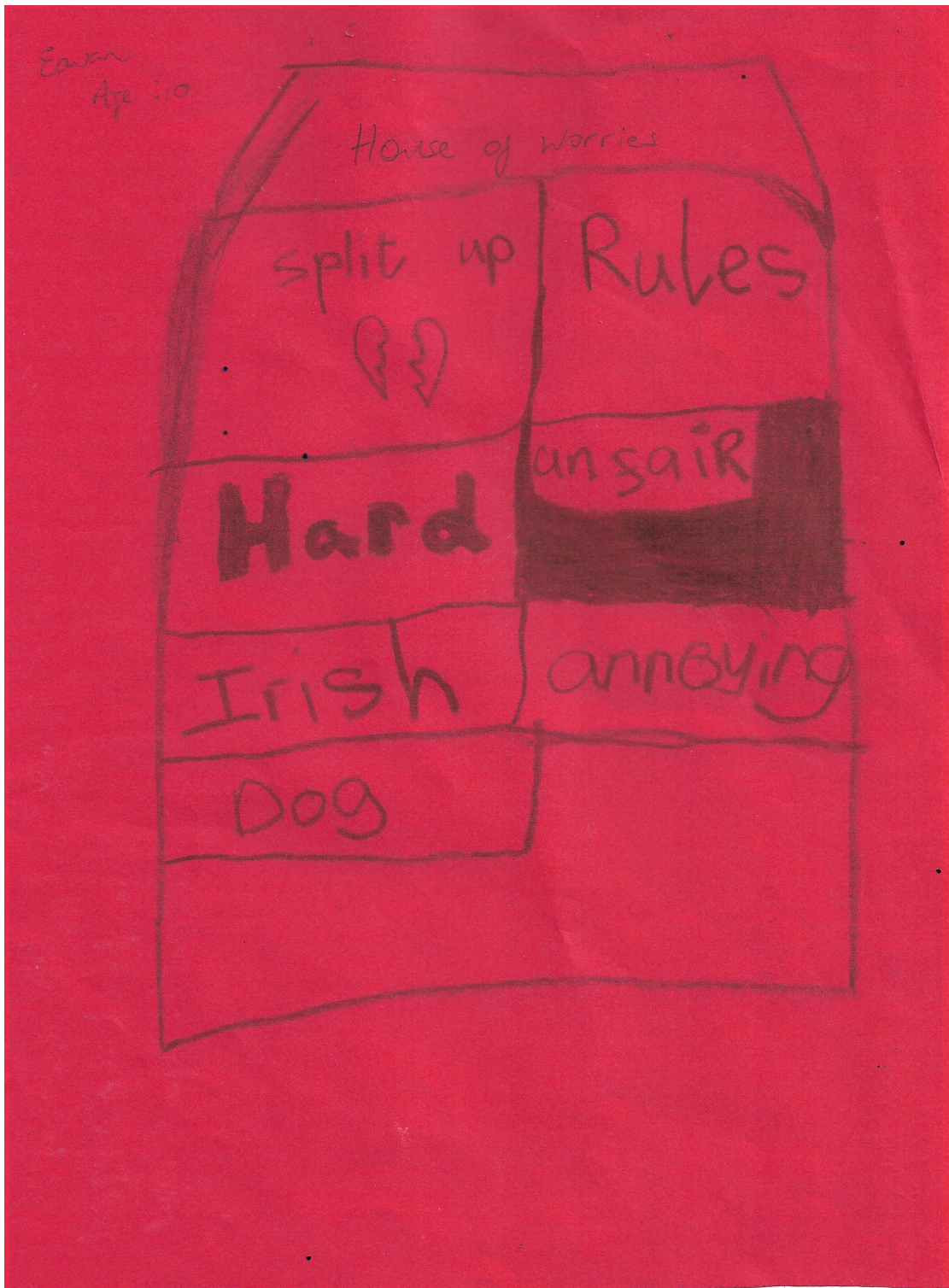
Gina Aged 6 – House of Hopes & Dreams

For Gina this was a house where there was no 'George goes crazy, no slapping, no homework, no madness'. Gina was diabetic and dealing with her own health issues.



Elena aged 7 – House of Hopes & Dreams

Elena's hope was that her brother John would talk some day and ask her to play with him.



Eavan Aged 10 - House of Worries

Eavan's sister Elizabeth was exempt from Irish at school and was getting an autism dog.

## CHAPTER SEVEN

### DISCUSSION AND CONCLUDING COMMENTS

#### Introduction

#### Reflections on the Research Process

From its inception, this thesis aimed to answer one central research question, *'How do typically developing siblings of autistic children experience the parent child relationship?'* In endeavouring to answer this, it was argued in Chapter Three that the research question was concerned with understanding subjective lived experiences, and therefore it was anticipated that a qualitative research approach would give rise to a variety of perspectives, allowing a holistic, multi dimensional view of participants' experiences to emerge.

Taking an interdisciplinary approach that draws on both psychological and sociological theory, varied multidimensional accounts of families who are raising an autistic child have been presented here, underpinned by epistemological and ontological positions outlined in Chapter Three. Participants' retrospective and current experiences of childhood and parenting, findings of which were reported in Chapters Four, Five, and Six, exposed the exceptional challenges and joys inherent in family experiences generated by having a child in the family diagnosed with ASD.

According to accounts here, these experiences come to bear on how the TD child reports experiences of their relationship with parents. Ostensibly, it appears the question of the parent child relationship involves two discrete parties: child and parent. However, what became apparent in undertaking the research was the infinite constellation of contextual variables, in addition to ASD, that inform the experiences of TD children (Meadan et al., 2010). Therefore, while common themes emerged, every participant child's experience of their parent in the context of ASD reported here, like every TD sibling who participated, was truly unique. Information from TD children about the quality of parent child relationships in this context is sparse, as Hastings (2014) found in his meta analysis of the

literature related to this issue. Though this study cannot claim to be representative of all TD siblings of autistic children living in Ireland, it has I hope successfully captured the authentic voices of the TD children who took part and has memorialised their accounts as informative and valuable in the area of social sciences.

A large amount of qualitative data was collected, transcribed, coded, and analysed to produce a contextually rich account of what young TD children had to say. For participating TD children, this was facilitated by the use of methods outlined in Chapter Three that allowed TD children communicate their views in an ethically prudent manner. Dialogues with TD children were marked by their enthusiasm, their competency, and their tenacity in a family situation acknowledged as researchers as stressful (Benson & Karloff, 2009; Burke, 2008). Participant children revealed themselves as active agents in, rather than passive witnesses to, their family's evolving story, and their acute awareness of the nuanced dynamics in the relationship with their parents was testimony to this. Rather than the '*tabula rasa*' proposed by philosopher John Locke (Winkler, 1996), it became clear that children are not blank sheets who wait for others to write on the pages of who they are, but instead they proved to be unique individuals with interior lives. That TD children can and want to 'make their mark' in their family and on the pages of research was abundantly clear in this project and this is discussed later in this chapter.

In Chapter One, a brief history of the child in an Irish context, an explanation of ASD, and debates around ASD was intended to contextualize the family life of participants. The review of extant research literature in Chapter Two demonstrated the centrality of adult accounts in research concerned with exploring the lives of families raising a child with autism (Dabrowska & Pisula, 2010; Hodge et al., 2011; Meirsschaut et al., 2010b), illustrating the absence of accounts directly from TD children, particularly on the issue of the parent child relationship, despite the fact that it can become dysfunctional in this context (Aronson, 2009; Fisman et al., 1996; Hastings, 2003; Vermaes et al., 2012). Findings in the current study are consistent with these existing research findings. However, no existing study of TD children in an Irish context did what this study has done, despite the fact that researchers are agreed upon the need for further projects informed by children's perspectives, which make siblings of autistic children more visible in the literature (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011, 2012; Opperman & Alant, 2003).

The impetus for this research was the absence of qualitative studies that explored this topic, derived directly from TD siblings, particularly in an Irish context. Just as a reader could not claim to know the experience of being orphaned by reading *Oliver Twist* (Dickens, 1839), I strongly believed that representations of TD children's experiences by parents or others in research could never quite capture the TD child's experience as accounts directly from TD children themselves would. While both TD children and parents were interviewed, the study specifically aimed to give centrality to the voice of the TD child, garnered directly from the TD children for reasons outlined in Chapter Three. Children's accounts were foregrounded by presenting their accounts of their experience of the home, parenting, and their relationships with parents in the context of ASD. It was hoped that key research questions would explicate interactions between parent and TD child, and shed light on shared experiences, needs, tensions or contradictions, if any, that may present in the accounts of each group. To restate, the broad research questions in interview concerned:

1. How do TD children experience the parent child relationship in the context of ASD?
2. Do children perceive their childhood as being sometimes shaped by ASD?
3. How do parents experience the parent-TD child relationship?
4. Do parents perceive that parenting / the parent-TD child relationship is sometimes shaped by ASD?
5. What experiences do children and parents identify as influencing their experiences of and the quality of their relationship?
6. Do parent-reported experiences intersect with issues children identify as important to them?

This qualitative, inductive study gave primacy to the experiences of the TD children, supplemented by and triangulated with parents accounts, and explored how all participants understood and managed their experiences. Additional dimensions to participant accounts were derived from evidence collected from reflective field notes and demographic information from parents gathered prior to and after interview proper. To review, 35 interviews were conducted with 15 TD children, 12 mothers, and eight fathers, and the material disclosed therein informs much of the discussion that follows.

The discussion that follows revisits the Irish context, explores the experiences of TD children and their parents, as recounted in interview, and discusses the findings related to

these. The discussion also identifies key aspects of TD sibling's experience in an attempt to explore the significance of these in particular, in relation to the research question and in the context of existing studies.

### **The Irish Context Revisited**

In Chapter One, through the lens of the new sociology of childhood (James, 2014), the history of culturally informed constructs of the child and childhood in Ireland demonstrated the fluidity of these concepts. From the positioning of the child in the Irish Constitution (1937), to the amendments to that same constitution discussed in Chapter One, the socio-political landscape of Ireland has transformed in recent decades, and attending to these changes is a growing awareness of childhood as an identity and a repositioning of children as important subjects and holders of rights (Hayes, 2002).

In the 'battles' surrounding the rights of children in Ireland (Nolan 2007), developments such as UNCRC (1989), the introduction of an Ombudsman for children (2002), policy documents such as *Our Children – Their Lives: National Children's Strategy 2000 -2010*, the establishment of the Child and Family Agency (2014) and more recently, the current national policy framework for children, '*Better Outcomes Brighter Futures: The National Policy Framework for Children & Young People 2014 – 2020*' combine to constitute a marked attempt by Irish policy makers to extend and protect the rights of children living in Ireland in line with international statute. If Arundhati Roy (2004) is correct in her assertion that there is really no such thing as the 'voiceless', only the deliberately silenced or the preferably unheard, such legislation ensures that the former social and political aversion to hearing children is no longer an option.

Literature from Uprichard (2008), also discussed in Chapter One, explored discourses around children as agentic human beings versus human becomings, and the approaches to interacting with children anchored in each. Bluebond-Langer's (2000) treatise on children growing up in the shadow of chronic illness illustrates manifestations of such discourses that can result in children being excluded from family situations of which they are very much a part, emanating perhaps from discourses around children that frame them as in need of protection. Additionally Glasberg's (2000) study was informative, in that it specifically explored parents' beliefs about children's understanding of autism in relation to where they are developmentally, highlighting the limitations of these.

Chapter One culminated in a discussion of the TD sibling in an Irish context moving forward, and argued the importance of the voice of TD siblings in a policy climate increasingly oriented towards a care in the community approach to the care of individuals such as those diagnosed with ASD; particularly when considering the probability that many TD siblings will become caregivers in adulthood (Heller and Kramer, 2009).

### **The Parent-TD Sibling Relationship Revisited**

The findings in Chapters Four, Five, and Six confirm that TD children and their parents encounter a range of experiences related to changes in the family wrought by a diagnosis of a child's autism and its attending effects on the parent-child relationship. A number of issues that have significant implications for understanding the parent-child relationship in this context came to the fore, namely, a sense of ambiguous loss for the family; a sense of 'disappointed anticipation' that may characterize parent-child relationships in this context; the tenacious resilience exhibited by TD siblings regardless of challenges; and possibly most importantly the competence of young TD siblings in contributing to dialogues around these issues through participation in the research process here.

Findings in the current study which explored the journey of the family in relation to securing a diagnosis were consistent with existing studies that explore this issue (Carlsson et al., 2016; Crane et al., 2016; Ryan & Salisbury, 2012; Siklos & Kerns, 2007).

Participants shared how the TD child becomes overshadowed and is inadvertently dispatched to the background, even pre-diagnosis while the time-consuming process of consultations and appointments for the autistic child occupies the parent. Chapter Two discussed Mesman et al. (2016) who speak of 'ideal' mothers, sensitive to their child's every need, and the place of this construct in attachment theory. The experiences of participant mothers in the current study made it clear that mothers aspire to this 'ideal' even in the face of unrelenting stress that can be characteristic of life raising an autistic child. Participant fathers' accounts of their response to and processing of diagnosis mirrored existing research also (Burrell et al., 2017; Genesoni & Tallandini, 2009; Gray, 2003), in that accounts show that fathers in this context frequently position themselves as advocates for the family in their efforts to minimise the emotional impact of diagnosis, preferring instead to focus on the evolving practical requirements of family life that have changed.



Accounts from TD children about the experience of diagnosis demonstrated their astuteness in all issues related to their family. It became apparent that, rather than an inability to understand, it was a lack of information from parents that compounded any anxiety that TD children felt about diagnosis. Their awareness of and their ability to communicate dynamics within the family unit was noteworthy, particularly their ability to keenly measure their parents moods and stress levels, even when these were not overtly shared by the parent with the TD child.

Representations of the stress anxiety and depression that parents can frequently endure, evident in existing literature, (Benson & Karlof, 2009a; Dabrowska & Pisula, 2010; Gray 1998, 2002; Hodge et al., 2011; O'Moore, 1978; Plant & Sanders, 2007) were frequently echoed in parent accounts of family life in the current study. Participant parents spoke of exhaustion and impossible demands on their time and energy, each of which filtered down into their interactions with TD siblings in the family. Parent accounts confirmed the range of existing studies previously discussed that delineate the stresses of parenting in this context, and its effects on equitable parenting, parental mental health and family life for all members of the family unit (Abbeduto et al., 2004; Burrell et al., 2017; Cashin, 2004; Finnegan et al., 2014; Gray, 2002b, 2003; Griffith et al., 2010; Hodge et al., 2011; Meirsschaut et al., 2010b; Nealy et al., 2012; O'Moore, 1978; Phelps et al., 2009; Phetrasuwan & Shandor Miles 2009; Smith et al., 2010; Woodgate et al., 2008; Yirmiya & Shaked, 2005).

Parents reported their experience of the relationship with their TD child as rewarding and loving, but it was a relationship frequently made problematic by their context as they tried to reconcile the needs of all of their children. Accounts suggested that parents negotiate a tightrope – balancing, anticipating, and meeting the needs of all children in the family. As a result of this, participant parents acknowledged parenting in a permissive way on a 'good' day, and resorting to strict prescriptive practices on a 'tricky' day. Moreover, they conceded differential parenting of the TD sibling that could, on occasion, neglect to fully address and meet the emotional and physical needs of the child. Equally, several parents admitted the capricious nature of their expectations of the TD child that often did not take account of the child as a child, that is, their developmental stage and abilities.

Parent accounts also confirmed, as is noted in existing research, that parenting an autistic child meant that the home climate, a fundamental developmental context for children, was significantly changed by the presence of the autistic child (McHale, Simeonsson, & Sloan, 1984: 421). They acknowledged attitudes to parenting that were marked by an element of surrender to this fact when it was necessary. They added that despite their attempts to be ‘super parents’ (Deatrick et al., 1988; Ray, 2002; Rempel & Harrison, 2007; Woodgate et al., 2008), the amplification of the ordinary ‘push and pull’ of parenting that can happen in the context of chronic health conditions meant that they were powerless to protect the TD siblings from some experiences that they accepted, were potentially detrimental for the TD child (Boyle et al., 2004; Chan & Goh, 2014; Lobato et al., 1991; McHale and Pawletko, 1992).

Discussions with the children outlined in Chapter Six demonstrate that their sense of ‘self’ as a child in need of consistent predictable care, their childhood experiences, and their relationship with each parent, were principally determined by the presence of their autistic sibling in the home. Alterations to family life, which TD children experienced largely as changes in their parents, were evident in that TD children explicitly and implicitly spoke of the parent as less available to them, and this was primarily discussed in terms of parental attention. By default, each TD child was involved in the stresses and challenges that present in the family, regardless of the parents’ intentions. Children expressed their awareness of how their emotional and physical needs had tumbled down a hierarchy of needs dominated by the needs of their autistic sibling (Henderson et al., 2011; Phetrasuwan & Shandor Miles, 2009; Plant & Sanders, 2007; Woodgate et al., 2008) and like their parents they ‘surrendered’ to this reality on occasion as certain occurrences in the home and in the relationship with the parent became normalised by their frequency.

The support needs of the autistic child were well articulated by the TD children in this study and were closely aligned to previous research which describes and documents such needs and behaviours and TD siblings understanding of them (Ferraioli & Harris, 2009; Griffith et al., 2010; Johnson & Rodriguez, 2013; O’Moore, 1978; Rodgers et al., 2012; Woodgate et al., 2008). In their experience of the parent child relationship, one of the most frequently cited issues by participant TD children was their experiences of differential parenting as a result of the autistic child’s needs, as noted above, and the majority highlighted the feelings of loss and resentment that could result from this (Boyle, 2004; Lobato et al., 1991; McHale and Pawletko, 1992).

This study also described participant children's attempts to manage these experiences and their efforts to maintain the relationship with the parent in the face of the challenges they encountered. Children's accounts suggested their desire to be involved in all issues emerging for the family. This became evident in parent accounts also where parents reported the 'mothering' and 'minding' of the autistic child and the parent by TD siblings. This was not devoid of stress for the TD sibling. Their reported strategies to manage stress can be understood through the lense of attachment theory, as TD children variously used defense mechanisms (Cramer, 2015), acted out negatively (Dreikurs et al., 2004), or became caregivers and 'good' children (Chase, 1999; Jurkovic, 1997; Sahoo & Suar, 2010; West & Keller, 1991) in their efforts to assuage feelings that threatened to overwhelm them, and in their attempts to stay connected to the parent (Ainsworth & Bell, 1970; Bowlby, 1990; 2008).

In relation to the experience of the parent child relationship, the most striking experiences shared by both children and their parents were; the feelings of ambiguous loss encountered by both child and parent; the nature of the parent child relationship in this context related to this loss; and the resilient tenacity exhibited by the children and their parents to protect their relationship despite some challenges they lived with. The significant findings of this study, namely, ambiguous loss, disappointed anticipation, and family resilience are each discussed in the following sections. In addition, the final significant finding discussed, is the remarkable engagement with the research process by the participant children who took part in the present study.

### **Ambiguous Loss for the Typically Developing Sibling**

Ambiguous loss is defined by Boss (2009) as a '*relational disorder*' caused externally by context rather than individual pathology. The first notable finding in the current study was that, as a result of their context, some TD siblings were quietly struggling - enduring many of the hallmarks of Ambiguous Loss (Boss, 2000) as discussed in Chapters Two, Four, Five, and Six. Ambiguous Loss can be considered a significant stressor for families who experience it. This stressor – frozen grief caused by irresolvable loss – had a marked effect on the parent child relationship for all families in the current study. Though all participants recounted a change to life as they had known it, none identified such change as ambiguous loss (Boss, 2000), despite the participants' own characterisations of family relationships

that would classify it as such. Namely, each participant reported experiences of complicated grief without socially recognized markers; chronic sorrow, with no clear and definitive understanding of the loss; a loss of certainty around family roles and relationships, and boundary ambiguity, each of which are discussed in earlier chapters.

For TD siblings experiencing ambiguous loss, the situation they live with is stressful and devoid of concrete answers. In the case of a diagnosis of ASD, grief becomes complicated because there are so many unknowns which can impede the usual grieving process (Boss, 2000). Because the aetiology of ASD remains uncertain, the family struggle to understand how or why their child is autistic and this was evident in accounts in the current study. Moreover, many participant parents had no clear idea of how their autistic child might develop in the future given that prognoses are broad ranging in the ASD spectrum. At the time of interview many families had been living with this uncertainty for several years. In relation to TD siblings, parent concerns extended beyond the present, years into the future, as some contemplated the responsibility that might land on the shoulders of their TD child when they were no longer around, particularly if the TD child had no other TD siblings. Heller and Kramer (2009) find that it is siblings who frequently become caregivers when parents cannot fulfil this role, yet reports in the current study suggested that often young TD siblings were 'locked out' of information and decision making in parents efforts to protect them. Ironically, this often exacerbated anxiety for the TD child.

As a result of this loss, and consistent with existing studies, varying degrees of anxiety, stress and depression were reported by all participants (Benson & Karlof, 2009; Dabrowska & Pisula, 2010; Gray 1998, 2002; Hodge et al., 2011; O'Moore, 1978; Plant & Sanders, 2007; Smith et al., 2010; Tehee et al., 2009; Woodgate et al., 2008; Yirmiya & Shaked, 2005). All participants articulated that these feelings resulted from the psychological challenges they encountered, linked to the loss associated with the autistic child's condition. Several parents also reported comparable challenges for their TD child. Yet only one parent voiced the possibility that their TD child might be grieving, stressed, or depressed as they were themselves. It seemed that TD siblings were set apart and were somehow to quietly absorb their loss in ways that parents themselves could not.

With the exception of one mother, none of the parent participants in the current study recognised that the TD child had suffered a loss as significant as their own, or that the TD child was grieving and may be at risk of stress and depression as a result. With the exception of one mother, no parent reported this possibility being mentioned by

professionals around the family either, such as support counsellors or a general practitioner. Sibeoni et al. (2019: 335) argue that global management of the family in this context by professionals should include TD siblings and should view them as '*persons in distress*'. Loss that resulted in distress was expressed by TD children in this study in a variety of ways. In addition to tangible loss such as personal space, belongings or toys, children spoke of a loss of safety and privacy in the home as well as the loss of the parent and family life that many had previously known. Arguably, the child's loss in this context exceeds the parents' in that the child loses aspects of both their sibling relationship and their parent relationship to autism. Compounding this, the TD child grows up with the grief associated with such loss, coming to it as they do at an early age. Moreover, the child's capacity to understand and process this loss can be limited by their age and cognitive stage of development so they may need support with this (Glasberg, 2000).

As discussed previously, in other populations where children experience similar kinds of ambiguous loss, children may be more readily identified as '*persons in distress*' by professionals. For example, given social attitudes around drug use, children of drug users, who encounter comparable experiences of parenting marked by ambiguous loss (Merchling et al., 2018), are quickly identified as 'at risk' because of their context. The relational effects that drug use can have on parenting, as cited by Merchling et al. (2018), has much in common with the relational effects that the ASD context can have on parenting. However, TD children in the ASD home are not understood as 'at risk' by professionals or monitored in the way that children of drug using parents might be (Hayden, 2004; Woods, 1994). In the case of the ASD home, the risk for the TD child is in the family context, which is beyond the control of any family member. The autistic child will always be autistic therefore, the family context is not as amenable to resolution in the way that sobriety might facilitate permanent resolution in the home of the drug using parent. Given this, TD children as distressed persons in this context (Sibeoni, 2019) may need long term, age appropriate, consistent monitoring and support in processing their loss and coming to terms with changes to family life and the parent child relationship.

Boundary ambiguity consistent with Ambiguous Loss (Boss 2000) was also apparent in participant accounts and directly related to ambiguous loss for the TD sibling. Confusion regarding family roles was frequently reported by participants in relation to situations of high stress that occurred frequently in the home. In children's accounts, the loss of certain aspects of childhood was evident in the child's self reported inversion of the parenting role,

as they became care givers to their mother and/or father. Boundary ambiguity was also clearly evident in parent accounts that illustrated the parents' vacillation between having the TD children engage in such behaviours on certain occasions, and attempts by parents to protect TD children from age inappropriate responsibility on others. It was observed that parents acknowledged what research suggests are the potential negative implications of these behaviours for the TD child (Chase, 1999; Jurkovic, 1997; Sahoo & Suar, 2010; West & Keller, 1991). However, considering the demands of parenting in this context, several 'downplayed' its importance, citing their belief that children are resilient and will cope, beliefs shaped perhaps by constructions of children and childhood, as previously discussed.

This finding suggests the challenge for practitioners may be to actively characterise diagnosis as an ambiguous loss for TD children in the family and direct families to services that can support them through their grief. As findings in the current study show, ambiguous loss takes a toll on all family members, emotionally, physically, and behaviourally (Boss, 2000). Worry, anger, fatigue, stress, isolation, depression, and guilt can combine to cause instability in parenting and emotional expression; and this in turn can generate conflict between parent and TD child. Accounts here indicate that this kind of conflict is circular, recurrent, and is ultimately exhausting and fruitless for everyone involved. In this context, and in this family dynamic, findings here suggest that TD children should be viewed as 'persons in distress' (Sibeoni, 2019) and it is further suggested that all family supports and interventions should have TD siblings – and an acknowledgment of the TD sibling's loss – at their core.

### **Disappointed Anticipation and the TD Sibling – filling the definitional void**

Directly related to Ambiguous Loss, the second notable finding in the current study is the loss of certainty and predictability that characterizes the uniquely distinctive nature of the parent child relationship in the ASD home. Accounts here suggest that the experience of the parent child relationship in a home where one child is autistic is couched in a pervasive sense of what this study calls, '*disappointed anticipation*'. In the present study, every participant mentioned this previously unnamed stressor as framing all parent child interactions, and this is directly related to the ambiguous loss of certainty around the relationship.

How does this study define ‘disappointed anticipation’? Disappointed anticipation refers a specific stressor related to the attachment relationship as found in the current study. This term aims to fill a definitional void and is the researcher’s attempts to capture and communicate the fugacious quality underpinning interactions in the parent child relationship in the context of ASD. In attachment theory, proximity seeking behaviours are initiated variously by both child and parent with the objective of engaging each other in a mutually satisfying connection and interaction. The connection or interaction may be planned or spontaneous and is warmly anticipated by both. It can take the form of a conversation, time spent together at home or a special social outing. This study found that connection or attempts to connect were frequently impeded, cut short or completely blocked by the needs of the autistic child. This disruption was acknowledged by both parent and child as frustrating yet unavoidable. As a result, the status of / promise of connection between the typically developing sibling and the parent was precarious and outside of the control of either party. Thus, it could not be relied upon and connections between parent and TD child seemed to exist on moving ground, where nobody could predict what might move next.

All participants reported the parent-TD child connection in the context of ASD as precariously erratic. Whether it was a weekly activity such a piano lesson or an appreciably important event for the TD child such as a birthday, both TD children and parents made reference to the fact that making plans or making promises did not guarantee predictability for the TD children. Accounts demonstrated how the TD child’s and the parents’ anticipation of time together could not be relied upon in any certain way and was regularly disappointed at the last minute. As evidenced in all accounts, the circumstantial ‘thwarting’ of connection that characterizes the parent child relationship in this context frequently resulted caregiver instability which in turn caused regular conflict and disappointment for both TD child and parent. In addition, this kind of unpredictability increases stress for the TD child (Bowlby, 1990) a fact, which may be particularly problematic for TD children in this study given their developmental stage as middle school aged children as found by others (Collins, Harris & Sussman, 1995; Darling & Steinberg, 1993; MacCoby & Martin, 1983).

As described in Chapter Five, as adults parents indicated that they have the capacity to understand and accept such disappointments and last minute changes to plans. Parents reported such disappointment as a regrettable fact of family life. However, TD children

accounts of their experiences in Chapter Six showed they struggled with the instability and sense of unfairness inherent in their situation. The effects of disappointed anticipation on TD children also became apparent in parents accounts where parents reported covert hostility on the part of the TD child directed at the autistic sibling and this may be partly explained by their lack of inclusion in issues related to their sibling. Furthermore, the generalizing of anxiety by the TD child to every upcoming event in life, even when the plans were outside the domain of the family as discussed earlier, also suggested the significant effect that disappointed anticipation can have on TD siblings. The TD child's attempts to manage this also included withdrawing from the parent and family to self-soothe; the TD child's attempt perhaps to protect themselves from this disappointment.

Children's accounts implied that it was preferable on occasion not to want, rather than to want and be repeatedly disappointed. Manifest in parent accounts was the attending impotence they felt around this. It was clear from their interviews that parents desired to meet the needs of their typically developing children. All participants expressed the frustrations they felt regarding this, and the upset inherent in this for both TD child and parent. Several parents suggested that supports such as respite care, which could guarantee consistent time together for the TD child and parent, would be key for the family in addressing this.

This particular finding suggests that the attachment relationship between parent and child in this context runs the risk of being mired in frustration. The loss of certainty around the parent child relationship ensures that the needs of the TD child cannot be attended to in a consistent manner. Parent accounts showed that they had the unenviable task of reconciling the needs of all of their children while never quite managing to succeed in this consistently. In attachment theory, inconsistent parental responsiveness can contribute to insecure attachment (Main & Solomon, 1986) which research suggests may have consequences for the future psychosocial functioning of the TD child (Bowlby, 2010; Main et al., 1985). Longitudinal study links attachment history to a range of developmental outcomes, relating specific patterns of attachment to normal or pathological development (Groh et al., 2014). Furthermore, research finds that attachment history also informs internal working models that children use to negotiate their relationships with self and others, including parents, over their life span (Main et al., 1985; Mikulincer & Shaver, 2012; Bowlby, 1990).



When addressing this issue it should be noted that ASD is a chronic and lifelong condition, therefore the context of the family home will remain relatively consistent over time. Given this, it can be argued that when considering strength based family support, targeting the attachment relationship of the parent and the TD child should be a particular focus for practitioners so that episodes of ‘disappointed anticipation’ are minimized. As resilience researcher Masten (2016) argues, parenting practices are a variable amenable to change. Masten (2016) adds that strength based interventions anchored in supporting parenting practices have compelling corroboration in developmental resilience literature. Therefore, in cultivating and supporting resilience in TD siblings, it would seem that a strength-based approach to supporting the attachment relationship may enhance protective variables for the TD child. This in turn may be effective in addressing issues around disappointed anticipation and positively shaping the TD child’s experiences of the parent child relationship in this context.

### **Family Resilience and the TD Sibling**

The third notable finding in this study relates to family resilience and TD sibling resilience in particular. Accounts from participants, which gave voice to family management strategies and family communication, suggested their concerted efforts to foster resilience in all family members (Walsh, 2012).

Many TD siblings and their parents reported in engaging behaviours that had parallels with the Adlerian technique of ‘acting as if’<sup>5</sup>. By using this ‘fake it til you make it’ approach, they disrupted negative thinking and focused on framing attitudes, values and assumptions positively. Despite some difficult circumstances, TD siblings regularly iterated and reiterated their belief that they would be ‘*okay*’. Their resilient thinking combined to shape and inform positive emotional responses to stressful events whenever possible. Though participants reported that their approach was inconsistent, or that strategies often failed and communication sometimes broke down, the majority of TD siblings exhibited a tenacious determination in persevering in order to manage their situation on their own terms and defy negatives.

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<sup>5</sup> Psychologist Alfred Adler proposed a technique ‘acting as if’ which encourages the individual to behave as if they are already the person they would like to be, or are already in the situation they would like to be in, with a view to disrupting negative thinking to manifest the self and life desired.

All families reported being engaged with informal supports and a formal support group, and the majority saw this support as vital to the family's wellbeing (Clifford & Minnes, 2013; Schopler & Mesibov, 1984). The support group was integral to the social lives of the majority of families. While some older TD siblings complained that they 'had to' attend events organized by the support, in the main, TD siblings largely accepted participation in such support as a given feature of family life. Some added that getting to know other children in a similar home environment made them feel less 'worried'. Added to this were indispensable informal supports from extended family that acted as a 'safety net' and facilitated the TD child - parent relationship regularly. The role of grand parents, extended family members, and close neighbours was mentioned by several parents who used this support to reduce stress on difficult days or to allow them one to one time with their TD child.

The accounts of family life shared by participants in this study were both poignant and powerful. Participant parents and TD siblings communicated a variety of experiences, many of which were positive and others which illustrated the daily challenges endemic to this family context as previously discussed. Equally compelling was how participants matched, and attempted to balance difficulties by recalling events framed as triumphs – be it getting some time with alone with a parent or managing a successful family social outing. Such triumphs were described as consciously pursued by TD children and parents, each of whom engaged in planning and routines designed to result in achievable, enjoyable family intimacy. Moreover, TD children and parents described actively engaging each other in small but meaningful ways whenever the opportunity presented (Chan & Goh, 2014) and training their focus on the positive when possible.

While all participants spoke of the difficulties associated with this, and all expressed how their efforts were regularly thwarted, none expressed being deterred from trying. Particularly striking was the positive and determined attitudes of the young TD siblings who took part in the study. While participant parents expressed many concerns about their parenting, as can also be seen in existing studies (Deatrick, Knafl & Walsh, 1988; Ray 2002; Rempel & Harrison, 2007; Woodgate et al., 2008), they reported striving to be 'super parents', and in their children's eyes it seemed that they were succeeding. While many parents spoke of their own parenting in unforgiving ways, despite some grievances, this study found, as did Suchmann et al. (2007), that TD children reported far more positively on how they were parented than their parents might have anticipated.

This finding suggests the motivation of TD siblings and families in this context to adapt to life in the most functional way possible. In supporting the family, the goal for service providers might be to design a collaborative, individualised response to a family's needs and capacities. Findings here support the contention that this should ideally happen by including TD siblings, assessing the family's strengths, and then using these to inform outcome goals that support parenting. By extension, an improved quality of life for all family members, particularly TD children may result – particularly if TD children are viewed as persons in need of support in this process (Masten, 2016; Sibeoni, 2019).

### **Reflections on the Typically Developing Sibling in the Research Process**

The final finding in this study is related the research process – and the competence and enthusiasm with which participant TD siblings engaged in this. Feminist author Margaret Attwood (1984) argues that '*A word after a word after a word is power*'. In an endeavour that at times felt like the TD sibling vs. the blank page, the primary aim of this study was to empower TD siblings – that is, to bring the TD sibling's words to the pages of research in a manner that did justice to their individually shared experiences. Countering the sound of invisibility, and conveying the most extraordinary personal experiences, the TD children who participated in this study placed themselves firmly in the research process by transforming their worlds into words.

As a researcher, I was charged with finding a balance between ethical requirements in research with children and respecting the child's right to be heard as provided in policy previously discussed. Children are protected in research by adult gatekeepers, parents in the case of the study here, and in this protection it is assumed that the parent will act as proxy (Coyne, 2010), privileging the child's best interests. Many parents shared that they wanted their children to be heard and stated their belief that it was in the child's best interest to take part if the child consented. Several joked about how they as parents might be represented in their TD children's accounts. Others mentioned their child's curiosity and interest in taking part in the study. One parent in particular spoke of her child's '*delight*' that somebody was coming to the home to speak specifically with her rather than with her autistic sibling – a testimony perhaps to the child's previous experiences of exclusion. In interview, this particular child, who was six years old, eagerly began her 'three houses' task while earnestly engaging in conversation about her life. She wondered if she might become famous as a result of taking part in the study, a comment that was

striking, given that fame makes an individual as ‘seen’ and as ‘heard’ as they can possibly be.

As discussed in Chapter Six, many participant children in the present study expressed their feeling of sometimes being invisible in the family home, and this included feeling unseen by professionals who visited the home. The lack of reciprocity from their autistic sibling (Kaminsky and Dewey, 2001) was without doubt less of a concern for TD children than the lack of attention from their parent that left them feeling unseen. Attachment behaviours, triggered by stressful situations generated a pronounced need on the part of the TD child for connection to the parent (Bowlby, 1990). Ironically, a meltdown ensured that when the TD child needed to be seen or heard most, the needs of the autistic child ensured that they momentarily disappeared from view for the parent.

In this study, both TD children and parent accounts suggest that when the parent saw the child, they were often not ‘seen’ as a child with needs. Their status as young children was ephemeral, subjugated to the needs of the family unit in a given moment. Accounts showed that when family life was difficult, the TD child was variously seen by the stressed parent as; an ally or helper who was less in need of the parent, or obstinate and difficult if they demanded for themselves. As parents spoke of incidences in the home it became clear that despite their best efforts, parental expectations - when shaped by times of high stress - could be more closely aligned to expectations one might have of a young adult. In these situations, the spectacular collision of the parents’ expectations of the TD child and the TD child’s attachment needs meant that conflict often ensued.

Arguably, the issues discussed above have parallels in the research agenda. Interestingly, the literature review showed there were studies looking at autism that consulted directly with TD children about their experience of their autistic sibling or their experience of their peers – yet there were none examining their experience of the relationship with their parents. This may indicate a lingering attitude on behalf of researchers that sees issues of parenting as somehow inviolable, a subject not to be broached for fear that research endeavours will ‘overstep the mark’ into an area considered the sacred domain of family. Historically, children have been socially constructed in ways that diminish and conceal, so that in research, accounts of their lives are often subsumed in parent accounts or totally absent (James et al., 1998), as beliefs about their agency collide with beliefs about their incompetency or their need for protection (Coyne, 2010).

The last three decades have seen shifts in how we understand children and childhood, as children have been gradually accepted as agents, individuals, rather than adults in the making (James et al., 1998; Uprichard, 2008). The personal contributions made by the child participants in this project demonstrate the power of inclusive research with children. The fact that, as Gina age six said in interview, '*sometimes kids are very smaller than grown ups*', should not lead researchers to believe that they have nothing worthwhile to contribute. Nor should being '*very smaller*' render TD children invisible or dispensable in researcher endeavours concerned with ASD. It is suggested here that the responsibility of researchers involves not only soliciting children's accounts of their lives in this context, but hearing and responding to what children tell us.

### **Recommendations for Policy, Research and Practice**

Issues around disability and the family reach far beyond individual therapeutic interventions for TD siblings as previously discussed. Indeed, if findings here have demonstrated anything, it is that the family unit as a whole must be the focus of policy, research and practice if TD children and their family members are to be supported.

The metamorphosis of research findings into policy and practice is a complex process often shaped by funding, policy agendas – both national and international - and various stakeholders. As with many qualitative studies, findings here reflect the intricacies of lived experience that must be distilled and translated to evidence amenable to influencing policy, research and practice.

Evolving discourse has seen shifts in how neurodiversity is understood and by extension how we understand ASD. Advocates champion neurological diversity and celebrate the different world-views and competencies that autistic, dyslexic, bipolar, and other neurodiverse people have. Throughout the research conducted for the purposes of this doctoral thesis, no family spoke of neurodiversity. The literature review demonstrated the largely medicalized understanding of ASD that prevails. Data gleaned here suggests that in the main, professionals are not engaged with, nor do they demonstrate an understanding of ASD beyond the medical or beyond their own particular area of expertise.

The need to explore support issues around ASD, framed by the concept of neurodiversity informs a central overarching recommendation here. Further research is needed to develop an integrated approach to examine how family support services and practices align with a neurodiversity framework. Data generated by academic researchers is often considered the most legitimate type of knowledge to inform or support policy and practice. This can eclipse implicit knowledge from families at grass root levels and practitioners, whose experiences may be considered less qualified or legitimate. In this research, all families reported their sense that each government agency they encountered was a discrete entity – each separate to each other. Families in the current research reported an apparent lack of communication and cohesiveness where service provision was concerned.

Dialogues which incorporate all information has the potential co-create a pool of knowledge to address a fundamental weakness in how family support is currently undertaken. At a policy level, the development of a joint knowledge agenda where the interdisciplinary creation of information and the development of a system for learning and sharing expertise among all professional involved in service provision for families living in their context of ASD has the potential to improve provision. Such an approach may benefit research agendas and the application of findings in practice - so that developmental processes for all children, coping strategies for the family and well-being for all family members are best supported.

A consideration of any participant family in this study framed by Bronfenbrenners Systems Theory (1979) - as discussed in chapter 2 - highlights how families who took part in this research are coping on micro, mezzo and macro levels.

This study suggests that at micro levels and sometimes mezzo levels, families can fare well where they have some degree of knowledge around ASD and a sense of their own agency. TD children and their parents report the support of families and friends invaluable where it is available- particularly support by those who are educated about ASD. Similarly, many families proved proactive in sourcing support for all children and themselves through their local community and voluntary groups on social media.

On a macro level however the data from the present study suggest that this is where participants report feeling powerless. Since the launch of the policy framework, *Better Outcomes Brighter Futures 2014 -2020* discussed in earlier chapters, the findings of this

study suggest it is valid to question if life for families in need of support, such as the participants here has improved in a practical way that makes a difference for family life?

Data harvested by government from professionals, service providers, parents and children to ascertain the effectiveness of policy and inform future policy planning suggests policy is falling short of objectives. The *Policy Framework for Children and Young people 2023 - 2028 : Report on the Responses to the Public Consultation* (2022), reveals continued shortcomings in meeting the needs of families in two areas which are relevant to this study: 1) accessing disability support and services within education and health settings; 2) poor provision of mental health services and long waiting lists for health services.

Many of the families in this study reported on issues that echoed these findings. Families reported problematic disclosure of diagnosis, long waiting lists to access health and educational support services for children, and poor access to support for mental health services. Participants reported service access as inconsistent, differing from county to county, with families travelling to a different county in the hopes of getting supports sooner. Once services were accessed, diagnosis was imparted with no consistent adherence to the established protocols discussed in Chapter 3. Support for families that might help them process the diagnosis was not suggested by professionals. In most cases parents went home from the consultants office to trawl the internet with a view to educating themselves about ASD as a diagnosis, finding *their own* support for their ASD and TD children, finding *their own* support for themselves, and beginning *their own* individual, largely unsupported journey of understanding the educational and financial ramifications of their child's diagnosis.

Instead of taking individual accounts in this study as a 'universal' reality for all TD siblings and families in this context, it may be that we need to dismantle and unpack such accounts and talk about how they can inform the health service and research community's conversations around disability and how that in turn might inform policy going forward.

These findings prompt a second recommendation related to practice and how diagnosis is imparted by professionals. Diagnosis is the starting point for families. In the current study, no parent reported that diagnosis was disclosed as anything other than a problem. This presentation of diagnosis by clinicians trickled down into how parents understood and experienced diagnosis and how they in turn presented the news of their sibling's diagnosis to other children in the family. This study suggests that there is an immediate need for

research into the current protocols around how professionals impart diagnosis and how these might be revised. This would support best practice in training professionals to disclose diagnosis to families in manner which frames neurodiversity as a difference rather than a difficulty.

A third recommendation relates to practice around service access. Timely access to services for families is vital. The TD children who were the focus of this research, and indeed their parents, each reported a home climate that was quite stressful at times. Many expressed a need for support services including mental health supports. Research is needed to establish why there is such a variance in waiting lists for service provision depending on where a family lives. Future research should explore specific barriers that are contributing to such variances and how can government policy address this – all with a view to an equitable service that streamlines access to support, so that a family’s location does not determine how long the family might be on waiting list.

While this study set out to explore the TD child relationship with their parent, what became apparent in undertaking the research was the infinite constellation of contextual variables, in addition to ASD, that inform the experiences of TD children. The most striking finding was the determination of the TD child and parent to nurture their relationship despite challenges. Time was revealed as a valuable commodity in these families. Respite care for the child with ASD was frequently referenced by parents and children as a way to ‘free up’ time which could then be focused on the relationship with TD children. This finding prompts a fourth recommendation that further studies examine the role of respite care as a protective moderator for the relationship between the TD child and their parent in the context of ASD.

The relationships between research, policy and practice are diffuse. Policy informs research and practice which in turn informs future policy. A cohesive approach in policy research and practice as suggested earlier has the potential to bolster the flow of knowledge within and across these fields. Such interdisciplinary knowledge, used systematically to inform future research, may result in cultural and social change that benefits TD children and their families.



## Concluding Comments

*'Among the most supported theories is that what is actually most useful about telling, goes further than simple stress release; putting our experiences into words helps us begin to make sense of our thoughts and feelings. Remember, especially for children ... words are labels and categories ... So when we talk about our experiences we are sorting them out ... the very act of doing so makes our most confusing or disturbing experiences more organized and understandable, and it makes them less scary and upsetting as well ... putting feelings into words can be a restoration of order.'*<sup>6</sup>

Echoing psychologist, Meg Jay, this study has found that in putting their stories in words and pictures, the small group of typically developing siblings of autistic children in Ireland who took part in this study have shone a light into the private corners of their world, and have given voice to experiences not previously accessed by the research community. Although in this project the participant children's numbers are small, this does not detract from the compelling power of what they have to say.

The study demonstrates that in the experience of participant TD children and their parents, life in the context of ASD is unique. The transition from family life pre autism to life living with an autistic can be fraught with stress and requires many accommodations by the family. While this finding is not new, this study specifically documents TD children's testimonies of this as important members of the family unit, and this is new.

The study demonstrates that, as a result of having an autistic sibling, the TD child experiences reduced one to one time with the parent, unwanted disruption and intrusion in their lives and unwanted responsibilities. These experiences inform the parent child relationship for the TD child, and this is the contribution the research here makes to existing studies, placing as it does some first hand accounts from TD siblings in the child shaped silence that has existed to date. The study has examined how the participant children make sense of their identity as sibling of an autistic child, how they negotiate the relationship with the parent in light of this, and how they strive to experience the relationship with their parents - and their childhood - in as typical a way as possible, in spite of challenges to their status as children. Instead of taking their individual accounts as a 'universal' truth for all TD siblings in this context, it may be that we need to deconstruct

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<sup>6</sup> Meg Jay ' *Super Normal, The Untold Story of Adversity and Resilience* (2017)

such accounts and examine how they can inform conversations around the efficacy of children when it comes to taking part in research concerned with autism.

Given research findings here with regard to the parent child relationship, this thesis concludes that the experiences of typically developing children in Ireland who have an autistic sibling are indeed singular, and from their perspectives, qualitatively different from their peers. Findings confirm the opening quote of this thesis cited in Chapter One, which describes life for the sibling of an autistic child as variously unpredictable and overwhelming, punctuated by the child's belief that this is manageable and they are 'okay'. Findings also imply that central for the TD sibling in managing life is the quality of their attachment to their parents.

In the light of findings related to ambiguous loss, disappointed anticipation, and family resilience, it is argued that the parent child relationship has the potential to act as the mechanism by which challenging experiences are moderated and made manageable for the TD child. Findings equally suggest that interventions which centralize the TD child and buttress the parent child relationship are necessary if long-term developmental trajectories for TD siblings are to be supported. It might be contended then, that the parent child relationship in the context of ASD can be a key protective mechanism for TD siblings and, so, is worthy of further empirical study. In doing this, it should be noted that the manner in which participant children in this study engaged with the research process highlights, not only their agency and capacity to participate in research about their lives, but more importantly their valuable contribution to research.

When engaging in research with children in the light of this, direct conversations with TD siblings by researchers may contribute to a research climate where accounts from TD siblings no longer '*live in the blank white spaces at the edges of print ... the gaps between the stories*'<sup>7</sup>. Typically developing siblings in this study have demonstrated the child's ability to write their own story, as consummate authors in the tale of who they are, how they live, and what they experience.

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<sup>7</sup> In *The Handmaids Tale* (1984), feminist author Margaret Atwood writes of women, '*We were the people who were not in the papers. We lived in the blank white spaces at the edges of print. We lived in the gaps between the stories.*'



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'After you hit a child, you can't just get up and leave him; you are hooked to that kid'

O. Ivar Lovaas Interview with Paul Chance. Retrieved

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# Appendices

## Appendix 1: Letter for Principals



### ***Study Title: 'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent-child relationship?***

My name is Paula Harrison. I am a PhD student with the Children's Research Centre and School of Social Work and Social Policy at Trinity College Dublin. I am conducting a research study and am writing to ask for your assistance with this project.

#### **About the study:**

In 2013 Irish Autism Action commissioned a study by a team of researchers from Dublin City University School of Nursing, 'Autism Counts'. The study confirmed that the prevalence rate of autism in Ireland is around 1%. Autism Spectrum Disorder is a complex and lifelong neurodevelopmental condition that also affects parents and non autistic children in families.

Parenting, and being parented in this context, presents a unique set of challenges as it is quite different to parenting children with other kinds of disability. We have some knowledge about how growing up with an autistic sibling affects developmental outcomes for typically developing children however, this is an under-researched area.

I would like to talk to siblings of autistic children between 6-12 years old, about how they experience the relationship with their parents. I will also talk with their parents about how they experience their relationship with their typically developing child.

#### **What will you be asked to do?**

I have prepared a letter of invitation, a copy of which is attached. If you are interested in facilitating contact, I would like you to forward it to all families who have children attending your school, one of whom attends the ASD class in the school, and the other, their sibling/s attending the mainstream school. This letter contains a brief description of the study and my contact details so that families can get in touch with me directly.

I feel that it would be best to interview the children in an environment that is familiar to them, where they feel comfortable. For this reason, I am asking that you would provide a room, with a glass panel in the door, on school premises where the interviews proper with the children could take place. Such a room will ensure that child protection procedures are adhered to, as a staff member can monitor proceedings. It also ensures confidentiality for the child. The interview with each child will take about 30- 45 minutes. Schools where interviews have taken place will not be identified in any way in research findings.

#### **What will happen during meetings with participants?**

I will initially meet potential participants in their home, for approximately 30 minutes. This first meeting will be an information meeting about the study. This will be an opportunity for the children and parents to ask questions and address concerns. Those interested in taking part will be invited to contact me directly to arrange a second meeting that will clarify any further issues. This will be followed by the interview proper with parents at the family home. For the children, the interview will take place in consultation with you, as previously outlined. Interviews will conclude with a debriefing session and information about support services.

### **What else do you need to know?**

ASD may be difficult for some families to talk about. To avoid causing unnecessary distress, it would not be advisable for families to participate if ;

- they are not currently engaged with support services
- their autistic child has been diagnosed less than 12 months ago
- there are other significant stresses happening for the family at this time because of divorce or berevment
- a potential participant child is presently experiencing personal challenges that may be stressful.
- the individual does not have a conversational level of English.

Participation in the study is entirely voluntary. Participants can withdraw from the study at any time, for any or no reason and without penalty.

Information will be strictly confidential and anonymous. Participants or schools will not be named or identified in any way. Names will be removed and replaced with codes.

Interviews will be audio recorded. The audio tapes will be transcribed. Typed transcripts will be encrypted and stored securely on a password protected desktop PC that only the researcher has access to. Once the study is completed these files will be destroyed.

This research will be written up as part of a dissertation for a PhD research doctorate. Findings may be presented at conferences or published in academic journals. All information will be anonymised.

If you would like to facilitate children's interviews or if you need further information about this study, please contact me on 086 1705853 or email [harrisp1@tcd.ie](mailto:harrisp1@tcd.ie). My supervisor is Dr Stephanie Holt - Email [sholt@tcd.ie](mailto:sholt@tcd.ie) or telephone 01 8963908.

Thank you for taking the time to read this.

Regards

Paula Harrison

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## Appendix 2: Information Sheets



### Invitation to be part of a Research Study

I am conducting research with families of children with ASD and I would be delighted if you decide to take part. I am interested in the experiences of children who have a sibling diagnosed with Autistic Spectrum Disorder. I am particularly interested in how they experience the relationship with you, their parents. I would like to talk with you also about how you experience the relationship with your non autistic child.

### A little bit about me...

My name is Paula Harrison. I am a PhD. research student at Trinity College, Dublin. I worked as a secondary school teacher for a number of years before opening a preschool in 2009 which provides Montessori and Naíonra education for children up to 5years old. I have many years experience teaching children ranging in age from age 3 to 18 years and working with their families. I have previously worked with autistic children, their siblings and parents, and this has prompted my interest in this research.

### What you have to say is important!

Listening to what families have to say about living with a child with ASD can help us better understand what this condition means for all family members. Talking to parents and children may help us find out how supports might be best improved for typically developing siblings

### If you decide to be part of this study:

- I will meet with you, and with your permission, your child, twice, for approximately 45 -50 minutes each time.
- The first meeting will be an information session about the study and will take place in your home. This will be an opportunity for you to ask questions and learn more about the background of the study and what it hopes to achieve. We will also discuss the interview process and all that it involves. Should you agree to participate, the second meeting, also in your home, will be to clarify any questions that you or your child have. This will be followed by your interview. I will ask you a number of questions, some of them about yourself, some about your family.
- With your permission, and your child's consent, I will talk seperately to your child by interviewing them at a later date about the same things. It is your decision to talk to me and you and/or your child can change your mind at any time and leave the study.
- You do not have to answer a question if you do not want to. You decide what and how much you tell me. We can take breaks during our conversation. You decide when to take a break and for how long.



- I will not use your real name at any time or the names of people or places that you talk about.
- What you tell me is confidential unless I think you will harm yourself or somebody else. In that case, I will talk to you about getting help.
- What your child tells me is also confidential unless your child tells me something to cause concern about your child's safety. If this happens I may need to talk to someone else.
- You will have no access to the information contained in your child's interview and they will have no access to the information contained in yours.
- If it is ok with you, I will use a voice recorder. This will help me to accurately remember what you said later on. Only I will listen to the recording.
- I will save all documents resulting from our conversation on a password protected computer that only I can access.
- It is possible that I will use examples of what is said in my research or in another paper or presentation but this will be anonymous. It is also possible that this research will be published and again, real names will never be used.
- **Are there any benefits or rewards for taking part?**
- There are no immediate benefits. However, what you tell me will contribute to knowledge around how children and parents experience their relationship in a family where a child is diagnosed with ASD. This information may be useful for services who provide support systems for families in the future.
- **Is there anything else you should know?**
- You should not take part in this study
- Unless you are already engaged with support services,
- If your child has been diagnosed with ASD less than 12 months ago or if your family is currently experiencing other significant stress because of a divorce or a bereavement.
- Your child should not take part if they are experiencing any personal challenges at the moment because of bullying for example. In that case it would be better to talk with someone who can support you and/or your child in relation to those issues.
- If you do not have a conversational level of English

**Remember: What you have to say matters. Talking to parents and children who live with ASD may help us find out how support can be best improved for families in the future.**

If you want to know anything else about this study, or if you have a question, please contact me. My mobile number is 086 1705853 or email [harrispl@tcd.ie](mailto:harrispl@tcd.ie). My supervisor is Dr Stephanie Holt - Email [sholt@tcd.ie](mailto:sholt@tcd.ie) or telephone 01 8963908.



## **Information Sheet (Parent)**

### *'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent-child relationship?*

You and your child are invited to take part in a research study concerning families of children diagnosed with Autistic Spectrum Disorder. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks, and benefits of this research study. If there is anything that you are not clear about, I will be happy to explain it to you. Please take as much time as you need to read this information sheet and discuss it with others if you wish. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for taking the time to read this.

### **What is this research about?**

This research is interested in learning more about parent child relationships. The study aims to find out how non autistic children experience their relationship with their parents and to hear about parent's experiences of their relationship with their non autistic child. The information you and your child provide may contribute to a body of knowledge about parenting in the context of ASD, and the experiences of non autistic children in the family. Such information may be useful in understanding how to best support families raising a child with a diagnosis of ASD in the future. To gather this information, I would like to meet with you and your child separately, to learn from you about your experiences. Taking part in this research is entirely voluntary; you may opt out at any time before, during or after the interviews. If you decide you do not wish to take part, this will not affect services you currently get or may want to get in the future.

### **Are there families who cannot take part in this study?**

In order to safeguard your well being and that of your family, you should not take part in this study if;

- You are not currently engaged with a support service
- Your child was diagnosed with ASD less than 12 months ago
- You are currently experiencing stress as a result of a divorce or berevement
- Your child is currently experiencing significant stress.
- You do not have a conversational level of English

### **What does taking part involve?**

**For you:** If you choose to participate you will be invited to take part in an interview that will take about 45 - 50 minutes to complete. With your agreement, this will take place at your home, at a time that is convenient for you. With permission, I will audiotape the interview to help to record what you have said accurately. Your child will not have access to any information you give me, nor will you have any access to information given to me by your child.

**For your child:** If you consent to your child being invited to take part, and your child agrees to participate, an interview that will take about 40 minutes to complete will take place at a time and space agreed with you both. This interview will be separate to yours. With permission, I will audiotape the interview to help to record what is said accurately.

Some of the broad areas I would like to discuss are:

- Your child's beliefs and understanding of their sibling's ASD as you understand it.
- Your child's understanding of ASD.
- Your experience of your relationship with your non autistic child; for example, communication, parenting, problem solving, joint activities.
- Your child's experience of their relationship with you.
- Your thoughts and your child's thoughts on how this relationship can be best supported.

At the end of the interview, we will discuss how you found the experience and how you are feeling. I will do the same with your child. Talking about these issues may be

upsetting. You are free to stop the interview and withdraw from the research at any time if you do not wish it to continue. Your child will also be reassured of this and given instructions on how to do this. If the interview upsets you or your child and you feel you would like some additional help afterwards, I will be able to advise you on who to contact.

### **What happens to the information?**

The information will be written up in a final report for my PhD and may be used in conference papers or seminars. All information will be confidential and anyone who takes part in the research will not be identified. Code numbers will be used instead of names. I will remove all names of people and places mentioned during the discussions when I type up our conversations. You or your child will not be named or identified in any way. While all interviews are fully confidential, if there are any safety concerns regarding you or your child that come to light in the course of the interviews, I may need to speak to someone else.

### **Are there any risks?**

There are no risks anticipated with participating in this study. However, if you or your child experience any distress following participation you are encouraged to inform me and I will be able to advise you on appropriate support.

### **Are there any benefits to taking part?**

There are no direct benefits in taking part, however the information you and your child provide may contribute to our knowledge about parenting in the context of ASD and the experiences of non autistic children in the family. Such information may be useful for services in understanding how to best support families raising a child with a diagnosis of ASD in the future.

### **How do I get involved?**

Taking part is your decision and you can change your mind and opt out of taking part, before during or after the interview has taken place. If you agree to take part, I will ask to ask you to sign a Consent Form for your participation and a consent form which allows me to ask your child to participate. Your child will also sign a child friendly version of the consent form which you can read. If there is anything that you are not

clear about, I will be happy to explain it to you when we meet. Consider your decision carefully and if you think you would like to be part of this study, or if you have a question before reaching a decision, you can contact me:

Email: [harrisp1@tcd.ie](mailto:harrisp1@tcd.ie) or telephone 0861705853

**Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact:

Researcher: Paula Harrison. Email: [harrisp1@tcd.ie](mailto:harrisp1@tcd.ie) or telephone 086 170853

Supervisor: Dr. Stephanie Holt. Email [sholt@tcd.ie](mailto:sholt@tcd.ie) or telephone 01 8963908.

## INFORMATION SHEET FOR CHILD PARTICIPANTS AGED 6-12 YEARS OLD



School  
of Social Work  
and Social Policy

## INFORMATION SHEET (CHILD AGED 6-12 YEARS OLD)

*'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent child relationship?*



Hi! I am doing a research study with children who have a brother or sister who is autistic and I would like to ask for your help.

### *What is a research study?*

Research means finding out more about something. It is a way to try to find out answers to questions. I am asking you to help me to answer questions because you have a brother or sister with autism and I believe that what you have to say is important.



### *Why am I asking these questions?*

Many children grow up in a family with a brother or sister who is autistic. I am interested to find out about your relationship with your parents. Talking with you means that I can hear directly from you about how you feel and what your experiences are.

### *Do I have to take part?*

You do not have to take part. You can say no and nobody will be cross or upset. If you say yes but later change your mind, that's ok too. Just tell me or your parents that you do not want to take part. Please take as much time as you need to think about taking part.

### *Will anybody know that I am in this study?*

Your name and anything you tell me will be private. This means that nobody will know what you have said. At the end of our talk, we will have a chat about how you are feeling. If you are upset in any way, you should tell me and I will help arrange for you to talk with an adult that you trust until you feel better.

### *What happens if I take part?*

If you want to take part, we will meet;

- I will ask you to answer some questions. I will not talk to your parents or anybody else about what you have told me.
- I will record what you say on a tape recorder so I don't forget what you have said.
- You will not have to answer any questions that you don't want to.
- If you want to stop talking, all you have to do is say 'stop' and we will finish our talk.
- If I am worried about you, I might want to talk to another grown up about it. If this happens I will talk to you before I talk to anybody else.
- When we are finished, I will write about what you have said.

### *What do I do now?*

Take time to decide if you want to take part or not. If you have questions that your parents cannot answer, you and your parents can email me at [harrisp1@tcd.ie](mailto:harrisp1@tcd.ie) or call me on 0861705853 and I will try to answer the question for you.



Thank you for reading this information sheet.

If you have any questions about the study, please contact:

Researcher: Paula Harrison. Email: [harrisp1@tcd.ie](mailto:harrisp1@tcd.ie) or telephone 086 1705853

Supervisor: Dr. Stephanie Holt. Email [sholt@tcd.ie](mailto:sholt@tcd.ie) or telephone 01 8963908.

## INFORMATION SHEET FOR CHILD PARTICIPANTS AGED 6-12 YEARS OLD



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#### *What is a research study?*

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#### *Why am I asking these questions?*

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#### *Do I have to take part?*

You do not have to take part. You can say no and nobody will be cross or upset. If you say yes but later change your mind, that's ok too. Just tell me or your parents that you do not want to take part. Please take as much time as you need to think about taking part.

#### *Will anybody know that I am in this study?*

Your name and anything you tell me will be private. This means that nobody will know what you have said. At the end of our talk, we will have a chat about how you are feeling. If you are upset in any way, you should tell me and I will help arrange for you to talk with an adult that you trust until you feel better.

#### *What happens if I take part?*



If you want to take part, we will meet;

- I will ask you to answer some questions. I will not talk to your parents or anybody else about what you have told me.
- I will record what you say on a tape recorder so I don't forget what you have said.
- You will not have to answer any questions that you don't want to.
- If you want to stop talking, all you have to do is say 'stop' and we will finish our talk.
- If I am worried about you, I might want to talk to another grown up about it. If this happens I will talk to you before I talk to anybody else.
- When we are finished, I will write about what you have said.

### *What do I do now?*

Take time to decide if you want to take part or not. If you have questions that your parents cannot answer, you and your parents can email me at [harrisp1@tcd.ie](mailto:harrisp1@tcd.ie) or call me on 0861705853 and I will try to answer the question for you.



Thank you for reading this information sheet.

If you have any questions about the study, please contact:

Researcher: Paula Harrison. Email: [harrisp1@tcd.ie](mailto:harrisp1@tcd.ie) or telephone 086 1705853

Supervisor: Dr. Stephanie Holt. Email [sholt@tcd.ie](mailto:sholt@tcd.ie) or telephone 01 8963908.

## Appendix 3: Consent Forms



### Consent Form for Children aged 7-12 years old

*'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent child relationship?*



Thanks for taking part!

I have met with Paula Harrison who is a research student. She wants to find out about my experience of my relationship with my parents.

- I have been able to ask questions about the study. All of my questions have been answered and I understand what the study is about.
- Paula will record what I say on a tape recorder so she does not forget anything I say. I understand that nobody but Paula will listen to the recording.
- When we are finished, Paula will write about some of the things I said in her study. This is because what I have to say is important. I understand that Paula will never use my real name in any paper that she writes about this study. She will also change the names of any people or places that I talk about.
- Paula won't talk to anybody about the things I say. My parents will not know about anything I say. If Paula is worried about me she might want to talk to somebody else about it. She will tell me before she talks to anybody else.
- I understand that talking to Paula is my choice. I don't have to answer any questions if I don't want to. I can take a break if I want to. If I want to stop completely, all I have to do is say that I want to stop.
- Paula will make a photocopy of this letter for me to keep.

I am happy to talk to Paula about myself and my relationship with my parents.

Signed (child) .....

Signed (researcher) .....

Date .....



## Consent Form for Parent Participation

*'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent-child relationship?*

I \_\_\_\_\_ agree with talk to Paula Harrison (Doctoral Student, Trinity College, Dublin) as part of the above entitled research study.

I understand that:

- The researcher will talk to me about myself and my experience of my relationship with my non-autistic child.
- My participation is entirely voluntary. I am free to end the interview at any time and I do not have to answer any question that I do not feel comfortable with.
- All information that I give to the researcher will remain confidential and my name or any identifying information will not appear on any reports or publications that may result from this research.
- I will have no access to my child's interview.
- If the researcher is told something that indicates that a child might be in danger, she may need to talk to somebody else about this.
- I can change my mind about participation in the study at any time.

Signed \_\_\_\_\_  
Parent

\_\_\_\_\_  
Researcher

Date \_\_\_\_\_

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### Consent Form for Parent (Child's Participation)

I \_\_\_\_\_ agree that Paula Harrison (Doctoral Student, Trinity College Dublin) may seek my child's permission to participate in the research study entitled, '*Growing up with an Autistic Sibling*': *How do siblings of autistic children experience the parent-child relationship?*

I understand that:

- Paula will talk to my child about their experience of the relationship with his/her parents.
- Everything that my child talks to Paula about is confidential. My child's interview is completely confidential and I will not have access to it.
- If my child tells Paula something that indicates that he/she might be in danger, Paula may need to talk to somebody else about this.

I understand that I can change my mind about my child's participation in the study at any time.

Signed (Parent) \_\_\_\_\_  
(Parent) \_\_\_\_\_  
(Researcher) \_\_\_\_\_

Date \_\_\_\_\_



### **Consent Form for Parent Participation**

*'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent-child relationship?*

I \_\_\_\_\_ agree with talk to Paula Harrison (Doctoral Student, Trinity College, Dublin) as part of the above entitled research study.

I understand that:

- The researcher will talk to me about myself and my experience of my relationship with my non-autistic child.
- My participation is entirely voluntary. I am free to end the interview at any time and I do not have to answer any question that I do not feel comfortable with.
- All information that I give to the researcher will remain confidential and my name or any identifying information will not appear on any reports or publications that may result from this research.
- I will have no access to my child's interview.
- If the researcher is told something that indicates that a child might be in danger, she may need to talk to somebody else about this.
- I can change my mind about participation in the study at any time.

Signed \_\_\_\_\_  
Parent

\_\_\_\_\_  
Researcher

Date \_\_\_\_\_



## Consent Form for Parent (Child's Participation)

I \_\_\_\_\_ agree that Paula Harrison (Doctoral Student, Trinity College Dublin) may seek my child's permission to participate in the research study entitled, *'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent-child relationship?*

I understand that:

- Paula will talk to my child about their experience of the relationship with his/her parents.
- Everything that my child talks to Paula about is confidential. My child's interview is completely confidential and I will not have access to it.
- If my child tells Paula something that indicates that he/she might be in danger, Paula may need to talk to somebody else about this.

I understand that I can change my mind about my child's participation in the study at any time.

Signed (Parent) \_\_\_\_\_  
(Parent) \_\_\_\_\_  
(Researcher) \_\_\_\_\_

Date \_\_\_\_\_



### Consent Form for Children aged 7-12 years old

*'Growing up with an Autistic Sibling': How do siblings of autistic children experience the parent child relationship?*



Thanks for taking part!

I have met with Paula Harrison who is a research student. She wants to find out about my experience of my relationship with my parents.

- I have been able to ask questions about the study. All of my questions have been answered and I understand what the study is about.
- Paula will record what I say on a tape recorder so she does not forget anything I say. I understand that nobody but Paula will listen to the recording.
- When we are finished, Paula will write about some of the things I said in her study. This is because what I have to say is important. I understand that Paula will never use my real name in any paper that she writes about this study. She will also change the names of any people or places that I talk about.
- Paula won't talk to anybody about the things I say. My parents will not know about anything I say. If Paula is worried about me she might want to talk to somebody else about it. She will tell me before she talks to anybody else.
- I understand that talking to Paula is my choice. I don't have to answer any questions if I don't want to. I can take a break if I want to. If I want to stop completely, all I have to do is say that I want to stop.
- Paula will make a photocopy of this letter for me to keep.

I am happy to talk to Paula about myself and my relationship with my parents.

Signed (child) .....

Signed (researcher) .....

Date .....

**Appendix 4: Family Demographic Questions – PLEASE CIRCLE YOUR ANSWER**

Name: \_\_\_\_\_

Mobile \_\_\_\_\_ Gender \_\_\_\_\_

1. How old are you?

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- Other

2. How old is your child who has a diagnosis of ASD?

.....

3. How old is your non autistic child/ren who will be interviewed?

.....

4. Including your autistic child, how many children are in the family? (please include ages of children)

.....  
.....  
.....

5. Marital Status: What is your marital status?

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated
- Other

6. Education: What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*

- No schooling completed
- Junior Infants to 6<sup>th</sup> class
- Some secondary school, no diploma
- Secondary school graduate : Junior Certificate or Leaving Certificate (please circle)
- Some college credit, no degree
- Trade/technical/vocational training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree



- Other

7. Employment Status: Are you currently...?

- Employed for wages
- Self-employed
- Out of work and looking for work
- Out of work but not currently looking for work
- A homemaker
- A student
- Military
- Retired
- Unable to work
- Other

8. What is your relationship to the child taking part in this study?

- Biological mother
- Biological father
- Stepmother
- Stepfather
- Other

9. What is your relationship to the child diagnosed with ASD?

- Biological mother
- Biological father
- Stepmother
- Stepfather
- Other

10. What gender is your child/ren taking part in this study?

- Girl ..... age.....
- Boy ..... age.....

11. What gender is your child who is diagnosed with ASD?

- Girl ..... age.....
- Boy ..... age .....

12. Does your child diagnosed with ASD have a dual diagnosis i.e., does your child have more than one disability? (please circle) No Yes

If your answer is yes, please explain below

.....  
.....  
.....  
.....

13. Do you live in....

- Dublin          Outside Dublin

14. Your email address / phone number for contact

.....

...

15. Best time for contact..... Worst time for  
contact.....

## Appendix 5: Interview Schedules

### Parents

#### Pre-interview briefing

- Acknowledge the sensitive nature of the interview and thank the participant for their time so far.
- Talk through the information sheet allowing for any questions and remind participants of the limits of confidentiality.
- Inform the participant that they can stop at any time and do not have to answer any questions they do not want to. [L]  
[SEP]
- Sign the consent forms.

Given that talking to parents about their parenting may be a sensitive issue, the researcher will take a non-directive narrative approach that is conversational in tone. Taking the position that the parent is the authority on raising a family with an autistic child, the researcher will be lead by the parents' recall of their own story, and will use probe questions to explore specific topics sensitively. Initially the researcher will invite the parent to relay how they first learned about their child's autism and what that experience was like.

#### Interview Questions for Parents

##### **1. Open up a dialogue with the parent.**

'Can I take you back to the beginning and ask you to tell me, how you learned about your child's autism...?'

- (a) What was that like for you?
- (b) Did you/How did you explain this to your other child/ren? How was that for you?
- (c) How are you doing now? Stress? Mental health?

##### **2. Explore parent's beliefs regarding their child's understanding of their sibling's autism.**

'Can you talk to me about how your other child/ren responded to this news ....?'

- (a) What do you think your child/ren understands about their brother/sister's autism?
- (b) Do you have a sense of how your child might feel about having an autistic sibling?  
What do they say?
- (c) Do you think that having an autistic sibling has any affect on the other children in your family? How so?

**3. Explore parent's perspectives about the emotional climate in the home.**

'Can you take me through a full average day at home and what it feels like for you...?'

- (a) What does a good day at home feel like? Can you remember a really good day and talk me through it?
- (b) What does a difficult day feel like? Can you remember a really difficult day at home and tell me about it?
- (c) If you had to choose words to describe the atmosphere at home in general, what words do you think would best capture this? 3 words and why? How are you doing in general day to day?

**4. Explore parent's affection/ responsiveness to their non autistic child.**

What words would you use to describe your relationship with your non-autistic child...?  
Tell me about parenting them .....

- (a) Do you think that the type of day you are having effects this? Can you give me some examples of that?
- (b) How does that feel for you? Do you look forward to spending time with them? What gives you the most satisfaction? Whats the hardest? Do you worry about x?
- (c) What words would you use to describe your non autistic child? 3 words and why?  
Are you guys alike in any way?

## **5. Explore Differential Parenting**

‘You have x number of children at home, one of whom has a disability. Can you talk to me about how you manage that day to day.... For example how you manage your time, your attention, discipline issues ...?’

(a) Are their family ‘rules’ like , ‘You must keep your room tidy’? Does everyone have to follow the rules?

(b) How are disagreements between the children, or between you and one of the children resolved? Who is the disciplinarian?

(c) Do the kids think you are fair?

## **6. Explore Joint Activities/ Family time**

‘What do you all enjoy doing together as a family...?’

(a) Do you have one to one time with your non autistic child? How often?

(b) How does that feel for you? Does it go well? Do you enjoy that time?

## **7. Explore experiences most important to the parent in relation to the parent child relationship**

‘If a friend came to you and said their child had just been diagnosed with autism, and the friend was wondering if this might effect her relationship with her other children, what would you tell her? What, if anything do you wish you had known about how autism effects your relationship with your other children...?’

## **8. Explore parents’ feelings about how the relationship with their non autistic child might be supported?**

‘If you could wave a magic wand and make anything possible, is there anything that you think would be really useful for you in supporting your relationship with your non autistic child/ren?...?’

### **Debriefing post interview**

- Ask the participant if there is anything further they wish to add that has not been covered [SEP]
- Check-in with the person to see how they are feeling after the interview
- Discuss what might happen if we meet again outside the research space
- Remind them of the support services that are available
- Arrange a time with them to make a follow-up phone call to check they are okay
- Thank them for taking part

## **Interview schedule for children**

### **Pre-interview briefing**

- Introductions and some time spent time building a rapport with the child. [SEP]
- Talk through the information sheet allowing for any questions. [SEP]
- Ask the child if they understand and consent to taking part, reminding them of the limits of confidentiality.
- Tell the child that they can stop at any time and do not have to answer any questions that they do not want to. [SEP]
- Sign the consent form.

### **Interviews with Children (7-11 years)**

**Initially, the researcher will explore the child's understanding of their sibling's autism**

'How do you know x is autistic.....?'

'Do you remember the time that mum/dad told you about x being autistic? Can you tell me what you remember ...?'

- (a) How did you feel when you heard this news?
- (b) What do you know about autism now?
- (c) Do you think x's autism makes a difference to your life in any way? How?

#### *Children 7-9 years old*

While working with the younger children (7-9 year olds), in order to meet them at their level, the researcher will use the 'Three Houses' information gathering tool, (Weld & Greening, 2003) which is a visual tool, that is narrative in focus, allowing the children engage in both verbal and non verbal ways with the researcher about the issues that are important to them. Weld (2003) sees it as a tool that facilitates conversation which allows the child to voice what is happening in their world. This technique involves the child drawing three houses, 1. House of Good Things, 2. House of Worries, 3. House of Dreams and Hopes. Starting with the 'house of good things' the child draws people and

things she/he would put in this house, and then does the same with the other two houses.

This exercise will be done with a view to opening up a dialogue with the child, where the researcher will use the child's answers to explore topics similar to those explored with parents such as the emotional climate in the home, the relationship with mum/dad, differential parenting, and fun family time.

#### *Children 10-11 years old*

With older child participants, the researcher will read a vignette. In an imaginary situation, they find that one of their friends has just found out that their sibling is autistic. The researcher will ask the child to tell their friend what they might expect family life and the relationship with mum/dad to be like in this situation, and how they might expect to feel. The researcher will use their answers to explore topics with the children such as, the emotional climate in the home, their relationship with mum/dad, differential parenting, and fun family time.

#### **Debrief post interview**

Ask the child if there is anything else they want to add to their story. [SEP]

Check-in with the child to see how they are feeling after the interview. [SEP]

Thank the child for taking part.



## **Interview Schedules**

### **Parents**

#### **Pre-interview briefing**

- Acknowledge the sensitive nature of the interview and thank the participant for their time so far.
- Talk through the information sheet allowing for any questions and remind participants of the limits of confidentiality.
- Inform the participant that they can stop at any time and do not have to answer any questions they do not want to. [SEP]
- Sign the consent forms.

Given that talking to parents about their parenting may be a sensitive issue, the researcher will take a non-directive narrative approach that is conversational in tone. Taking the position that the parent is the authority on raising a family with an autistic child, the researcher will be lead by the parents' recall of their own story, and will use probe questions to explore specific topics sensitively. Initially the researcher will invite the parent to relay how they first learned about their child's autism and what that experience was like.

#### **Interview Questions for Parents**

##### **1. Open up a dialogue with the parent.**

'Can I take you back to the beginning and ask you to tell me, how you learned about your child's autism...?'

- (d) What was that like for you?
- (e) Did you/How did you explain this to your other child/ren? How was that for you?
- (f) How are you doing now? Stress? Mental health?

##### **2. Explore parent's beliefs regarding their child's understanding of their sibling's autism.**

'Can you talk to me about how your other child/ren responded to this news ....?'

- (a) What do you think your child/ren understands about their brother/sister's autism?

(b) Do you have a sense of how your child might feel about having an autistic sibling?

What do they say?

(c) Do you think that having an autistic sibling has any affect on the other children in your family? How so?

### **3. Explore parent's perspectives about the emotional climate in the home.**

'Can you take me through a full average day at home and what it feels like for you...?'

(a) What does a good day at home feel like? Can you remember a really good day and talk me through it?

(b) What does a difficult day feel like? Can you remember a really difficult day at home and tell me about it?

(c) If you had to choose words to describe the atmosphere at home in general, what words do you think would best capture this? 3 words and why? How are you doing in general day to day?

### **4. Explore parent's affection/ responsiveness to their non autistic child.**

What words would you use to describe your relationship with your non-autistic child...? Tell me about parenting them .....

(a) Do you think that the type of day you are having effects this? Can you give me some examples of that?

(b) How does that feel for you? Do you look forward to spending time with them? What gives you the most satisfaction? Whats the hardest? Do you worry about x?

(c) What words would you use to describe your non autistic child? 3 words and why?

Are you guys alike in any way?

### **5. Explore Differential Parenting**

'You have x number of children at home, one of whom has a disability. Can you talk to me about how you manage that day to day.... For example how you manage your time, your attention, discipline issues ...?'

(a) Are their family 'rules' like , 'You must keep your room tidy'? Does everyone have to follow the rules?

(b) How are disagreements between the children, or between you and one of the children resolved? Who is the disciplinarian?

(c) Do the kids think you are fair?

#### **6. Explore Joint Activities/ Family time**

‘What do you all enjoy doing together as a family...?’

(a) Do you have one to one time with your non autistic child? How often?

(b) How does that feel for you? Does it go well? Do you enjoy that time?

#### **7. Explore experiences most important to the parent in relation to the parent child relationship**

‘If a friend came to you and said their child had just been diagnosed with autism, and the friend was wondering if this might effect her relationship with her other children, what would you tell her? What, if anything do you wish you had known about how autism effects your relationship with your other children...?’

#### **8. Explore parents’ feelings about how the relationship with their non autistic child might be supported?**

‘If you could wave a magic wand and make anything possible, is there anything that you think would be really useful for you in supporting your relationship with your non autistic child/ren?...?’

#### **Debriefing post interview**

- Ask the participant if there is anything further they wish to add that has not been covered
- Check-in with the person to see how they are feeling after the interview
- Discuss what might happen if we meet again outside the research space
- Remind them of the support services that are available
- Arrange a time with them to make a follow-up phone call to check they are okay
- Thank them for taking part

## **Interview schedule for children**

### **Pre-interview briefing**

- Introductions and some time spent time building a rapport with the child. [L] [SEP]
- Talk through the information sheet allowing for any questions. [L] [SEP]
- Ask the child if they understand and consent to taking part, reminding them of the limits of confidentiality.
- Tell the child that they can stop at any time and do not have to answer any questions that they do not want to. [L] [SEP]
- Sign the consent form.

### **Interviews with Children (7-11 years)**

#### **Initially, the researcher will explore the child's understanding of their sibling's autism**

'How do you know x is autistic.....?'

'Do you remember the time that mum/dad told you about x being autistic? Can you tell me what you remember ...?'

- (d) How did you feel when you heard this news?
- (e) What do you know about autism now?
- (f) Do you think x's autism makes a difference to your life in any way? How?

#### *Children 7-9 years old*

While working with the younger children (7-9 year olds), in order to meet them at their level, the researcher will use the 'Three Houses' information gathering tool, (Weld & Greening, 2003) which is a visual tool, that is narrative in focus, allowing the children engage in both verbal and non verbal ways with the researcher about the issues that are important to them. Weld (2003) sees it as a tool that facilitates conversation which allows the child to voice what is happening in their world. This technique involves the child drawing three houses, 1. House of Good Things, 2. House of Worries, 3. House of Dreams and Hopes. Starting with the 'house of good things' the child draws people and things she/he would put in this house, and then does the same with the other two houses. This exercise will be done with a view to opening up a dialogue with the child, where

the researcher will use the child's answers to explore topics similar to those explored with parents such as the emotional climate in the home, the relationship with mum/dad, differential parenting, and fun family time.

*Children 10-11 years old*

With older child participants, the researcher will read a vignette. In an imaginary situation, they find that one of their friends has just found out that their sibling is autistic. The researcher will ask the child to tell their friend what they might expect family life and the relationship with mum/dad to be like in this situation, and how they might expect to feel. The researcher will use their answers to explore topics with the children such as, the emotional climate in the home, their relationship with mum/dad, differential parenting, and fun family time.

**Debrief<sup>[ ]</sup><sub>[SEP]</sub> post interview**

Ask the child if there is anything else they want to add to their story. <sup>[ ]</sup><sub>[SEP]</sub>

Check-in with the child to see how they are feeling after the interview. <sup>[ ] [ ] [ ] [ ]</sup><sub>[SEP] [SEP]</sub>

Thank the child for taking part.

## **Interview Schedule for children**

### **Pre-interview briefing**

- Introductions and some time spent time building a rapport with the child. [L] [SEP]
- Talk through the information sheet allowing for any questions. [L] [SEP]
- Ask the child if they understand and consent to taking part, reminding them of the limits of confidentiality.
- Tell the child that they can stop at any time and do not have to answer any questions that they do not want to. [L] [SEP]
- Sign the consent form.

### **Interviews with Children (6-12 years)**

#### **Initially, the researcher will explore the child's understanding of their sibling's autism**

'How do you know x is autistic.....?'

'Do you remember the time that mum/dad told you about x being autistic? Can you tell me what you remember ...?'

- (g) How did you feel when you heard this news?
- (h) What do you know about autism now?
- (i) Do you think x's autism makes a difference to your life in any way? How?

#### *Children 6-10 years old*

While working with the younger children (7-9 year olds), in order to meet them at their level, the researcher will use the 'Three Houses' information gathering tool, (Weld & Greening, 2003) which is a visual tool, that is narrative in focus, allowing the children engage in both verbal and non verbal ways with the researcher about the issues that are important to them. Weld (2003) sees it as a tool that facilitates conversation which allows the child to voice what is happening in their world. This technique involves the child drawing three houses, 1. House of Good Things, 2. House of Worries, 3. House of Dreams and Hopes. Starting with the 'house of good things' the child draws people and things she/he would put in this house, and then does the same with the other two houses. This exercise will be done with a view to opening up a dialogue with the child, where

the researcher will use the child's answers to explore topics similar to those explored with parents such as the emotional climate in the home, the relationship with mum/dad, differential parenting, and fun family time.

*Children 10-12 years old*

With older child participants, the researcher will read a vignette. In an imaginary situation, they find that one of their friends has just found out that their sibling is autistic. The researcher will ask the child to tell their friend what they might expect family life and the relationship with mum/dad to be like in this situation, and how they might expect to feel. The researcher will use their answers to explore topics with the children such as, the emotional climate in the home, their relationship with mum/dad, differential parenting, and fun family time.

**Debrief<sup>[ ]</sup><sub>[SEP]</sub> post interview**

Ask the child if there is anything else they want to add to their story. <sup>[ ]</sup><sub>[SEP]</sub>

Check-in with the child to see how they are feeling after the interview. <sup>[ ] [ ] [ ]</sup><sub>[SEP][SEP]</sub>

Thank the child for taking part.

## Appendix 6: List of Participant Family Profiles with pseudonyms

### List of Participant Family Profiles

FAMILY INTERVIEWS - CO. DUBLIN		
<p><b>Ellis Family</b></p> <p>Mother: Emer, Age 35-44 Education: Degree Employed: Caregiver in the home</p> <p>Father: Declined interview</p> <p>T.D. Sibling: Eavan, Age 10</p> <p>ASD Child: Elizabeth, Age 14 – plus ODD, ADHD, Language Impairment Dual Diagnosis: Yes – diagnosed age 11yrs</p> <p>Mother and Father are separated. No other children</p>	<p><b>Butler Family</b></p> <p>Mother: Liz, Age 35 - 44 Education: Leaving Certificate Employment: Caregiver in the home</p> <p>Father: Robert, Age 35-44 Education: Professional Diploma Employed: Outside the home - fulltime</p> <p>T.D. Sibling: Amy, Age 12 ASD Child: Conor, Age 5 - plus ADHD, Sensory Processing Disorder Dual Diagnosis: Yes – diagnosed aged 2yrs</p> <p>Mother and Father are married – TD participant sibling is not the biological child of Father. No other children</p>	<p><b>Garvey Family</b></p> <p>Mother: Gloria Age 35- 44 Education: Degree Employment: Caregiver in the home</p> <p>Father: Declined interview</p> <p>T.D. Sibling: Gina, Age 6 ASD Child: George, Age 5 Dual Diagnosis: No – diagnoses age 3yrs</p> <p>Mother and Father are divorced – family includes 2 other children, Geri, Age 3 &amp; Gary, Age 18</p>
<p><b>Jones Family</b></p> <p>Mother: Janice Age 25-34 Education: Junior Certificate Employment: Caregiver in the home</p> <p>Father: Declined Interview</p> <p>T.D. Sibling: Joe, Age 8</p>	<p><b>Hale Family</b></p> <p>Mother: Helen Age 45 -54 Education: Degree Employment: Inside of the home – part time</p> <p>Father: Hugh 35-44 Education: Masters Degree Employment: Outside the home - fulltime</p>	<p><b>Andrews Family</b></p> <p>Mother: Denise, Age 35 – 44</p> <p>Education: Leaving Certificate plus Vocational Training</p> <p>Employed: Outside the home - fulltime</p>



**FAMILY INTERVIEWS - CO. DUBLIN**

<p>ASD Child: Jill, Age 3- plus Global Developmental Delay Dual Diagnosis: Yes – diagnosed 1.5yrs</p> <p>Mother and Father of ASD child Separated Father of TD sibling participant child is deceased. No other children</p>	<p>T.D. Sibling: Harry Age 10 T.D. Sibling: Hilly Age 8 ASD Child: Henry, Age 4 - plus ADHD, ADD, ODD Dual Diagnosis: Yes – diagnosed age 2yrs</p> <p>Mother and Father are married – no other children</p>	<p>Father: Declined interview</p> <p>T.D. Sibling: Elena, Age 7</p> <p>ASD Child: John, Age 9 - plus ADHD, Hypotonia</p> <p>Dual Diagnosis: Yes – diagnosed age 3yrs</p> <p>Mother and Father are married. No other children</p>
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**FAMILY INTERVIEWS - RURAL**

<p><b>Kirwan Family</b></p> <p>Mother: Kate, Age 35-44 Education: Degree Employment: Outside home –part time</p> <p>Father: Declined Interview</p> <p>T.D. Sibling: Kyle, Age 11</p> <p>ASD Child: Kim Age 5 - plus developmental delay ASD Child: Karl Age 3</p> <p>Dual Diagnosis: Yes –Kim diagnosed age 3yrs No – Karl diagnosed age 1.5yrs</p> <p>Mother and Father are married. No other children in the family</p>	<p><b>Lawlor Family</b></p> <p>Mother: Declined interview</p> <p>Father: Larry, Age 35-44 Education: PLC course Employment: Self employed - fulltime</p> <p>T.D. Sibling : Lily, Age 6 ASD Child: Leo Age 8</p> <p>Dual Diagnosis: No – diagnosed age 6 yrs</p> <p>Mother and Father are married. No other children in the family</p>	<p><b>Murphy Family</b></p> <p>Mother: Marie Age 45-54 Education: Junior Certificate Employment: Caregiver in the home</p> <p>Father: Mark Age 45-54 Education: Degree Employment: Outside the home – fulltime</p> <p>T.D. Sibling: Milly, Age 10 ASD Child: Micah, Age 7</p> <p>Dual Diagnosis: No – diagnosed age 5 yrs</p> <p>Mother and Father are married – One other child in the family, Maggie, Age 14</p>
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**FAMILY INTERVIEWS - RURAL**

FAMILY INTERVIEWS - RURAL		
<p><b>Norton Family</b></p> <p>Mother: Nuala Age 35 – 44            Education: Leaving Certificate            Employment: Part time – one day per week out of home</p> <p>Father: Niall 35 - 44            Education: Degree            Employment: Full time working from home</p> <p>T.D. Sibling: Ned Age 10            T.D. Sibling: Nell, Age 6</p> <p>ASD Child: Noah, Age 8            Dual Diagnosis: No – diagnosed age 5 yrs</p> <p>Mother and Father are married – One other child in the family, Nikki, Age 2</p>	<p><b>Farrell Family</b></p> <p>Mother: Fiona, Age 35-44            Education: Degree            Employed: Caregiver in the home</p> <p>Father: Frank Aged 45 – 54            Education: Junior Certificate            Employment: Own business</p> <p>T.D. Sibling: Fionn Age 10            ASD Child: Fiachra, Age 4            Dual Diagnosis: No – diagnosed age 2.5 yrs</p> <p>Mother and Father are married – One other child in the family, Freddy Age 14</p>	<p><b>Duffy Family</b></p> <p>Mother: Sue, Age 35-44            Education: Degree            Employed: Outside of the home: part-time</p> <p>Father: Derek, Age 35-44            Education: Master’s degree            Employed: Outside of the home- fulltime</p> <p>T.D. Sibling: David, Age 9            ASD Child: Dylan, Age 7            Dual Diagnosis: No - diagnosed age 3.5 yrs</p> <p>Mother and Father are married –            no other children in the family</p>

