

**Using a Social Story™ with an adult  
diagnosed with a Learning Disability  
and Autism Spectrum Disorder:**

**A qualitative analysis of a mother and  
daughter's experience**

Nicol Aphilé

2012-2015 Cohort

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## **DECLARATION**

I, Nicol Aphilé declare that the work contained within this thesis is my own and is submitted purely for the purposes of the Doctoral Thesis for the Doctorate in Clinical Psychology and no other academic award.

# **Using a Social Story™ with an adult diagnosed with a Learning Disability and Autism Spectrum Disorder: A qualitative analysis of a mother and daughter's experience**

**By Nicol Aphalé**

## **ABSTRACT**

### Literature Review:

A meta-ethnography synthesised nine papers to explore the question 'How do family members of an individual with an autism spectrum disorder (ASD) make sense of their experience?' Papers included the experiences of parents, grandparents and siblings of an individual with ASD. Reciprocal translations synthesised eight themes; autism is not our relative, family life revolves around autism, the stress and strain of being a family with autism, tolerating that autism can bring aggression, families' accepting and seeking to understand autism, families' celebrate their relative's achievements and cherish happy moments, feeling judged and isolated by others, and fighting an inaccessible system. These themes provide insight into families' experiences and were considered in relation to a model of parental stress (Deater-Deckard, 1998). Recommendations for more qualitative research in the UK were made.

### Research Report:

*Background:* Social Stories™ are an intervention which provides contextual information to individuals with ASD (Gray & Garand, 1993). The evidence base for use with adults is limited and little is known about the experience of using this intervention.

*Aim:* This paper asked "What are the experiences of an adult diagnosed with a Learning Disability and ASD, and their carer who have used a Social Story™?"

*Design:* A participant and carer used a Social Story™ and participated in a semi-structured interview. Thematic Analysis (Braun & Clarke, 2006) was initially undertaken and Interpretative Phenomenological Analysis (IPA, Smith *et al.*, 2009) was subsequently undertaken to allow a more interpretative analysis of the data.

*Results:* Thematic Analysis highlighted the explicit cognitive behavioural, information processing explanations of the story's benefit. In contrast, the IPA illuminated a relational aspect of using the story, reflected in the over-arching theme; 'need to contain separation anxiety'.

*Conclusion:* These two psychological processes may be occurring in parallel when using a Social Story™ and this area requires further research.

### Critical Appraisal:

This paper offers reflections on the process of undertaking the thesis.

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## CONTENTS PAGE

### **Using a Social Story™ with an adult diagnosed with a Learning Disability and Autism Spectrum Disorder: A qualitative analysis of a mother and daughter's experience ..... 1**

Declaration.....	2
Abstract.....	3
Acknowledgements .....	4
Word Count.....	5
Contents Page .....	6
List of Tables .....	9
List of Figures .....	10
<b>Literature Review.....</b>	<b>11</b>
1. Abstract.....	12
2. Introduction .....	13
3. Method .....	15
3.1 Epistemological stance .....	15
3.2 Meta-ethnography.....	16
3.3 Literature Searching.....	16
3.4 Data extraction and analysis.....	17
4. Results.....	18
5. Discussion.....	24
References .....	30
<b>Research Report.....</b>	<b>35</b>
1. Abstract.....	36
2. Introduction .....	37
2.1 Prevalence of ASD and co-morbidity with Learning Disabilities.....	37
2.2 Current Guidelines and Recommendations.....	37
2.3 Social Stories™ .....	38
2.4 Evidence Base for the use of Social Stories™ with children (aged 3 to 12 years) .....	39
2.5 Evidence Base for the use of Social Stories™ with adolescents and adults (aged 13 to 57 years) .....	40
2.6 Criticisms of Social Story™ Research .....	41
2.7 Recommendations for Further Research.....	42
2.8 Aim of this Research Paper .....	42
3. Method .....	43
3.1 Study Design .....	43

3.2 Participants .....	44
3.3 Measures.....	44
3.4 Procedure.....	46
3.5 Data Analysis.....	46
3.6 Ethics.....	48
4. Results.....	48
4.1 Target Situation, Psychological Formulation and Creation of the Social Story™ .....	48
4.2 Behaviour Monitoring.....	49
4.3 Patient Rated Outcome Measure (PROM) .....	51
4.4 Thematic Analysis .....	51
4.5 Interpretative Phenomenological Analysis.....	53
5. Discussion.....	66
5.1 Discussion of Results.....	66
5.2 Social Story™ Application with Adults .....	68
5.3 Limitations of the present paper .....	71
5.4 Recommendations for further research .....	73
5.5 Conclusion.....	74
References .....	75
<b>Critical Appraisal .....</b>	<b>81</b>
1. Literature Review .....	82
2. Undertaking the Research Project: Challenges and Learning Experiences .....	83
2.1 Undertaking the research project.....	83
2.2 The evolving nature of the project .....	87
2.3 The analysis of experience.....	87
3. Hopes for Future Research .....	91
References .....	93
<b>Appendices .....</b>	<b>94</b>
Appendix A: Epistemological stance and explanation for selection of Meta-ethnography as a method of synthesis .....	95
Appendix B: Meta-ethnography process.....	97
Appendix C: Explanation of Search Terms used .....	98
Appendix D: Short-Listed Articles .....	99
Appendix E: The development of the Adapted Quality Appraisal Tool.....	102

Appendix F: Adapted Quality Appraisal Tool .....	103
Appendix G: Summary of the quality appraisal findings for included articles .....	104
Appendix H: Data extraction from nine articles included in meta-ethnography .....	106
Appendix I: Understanding Autism .....	110
Appendix J: Study Referral Form .....	112
Appendix K: Behavioural monitoring form .....	115
Appendix L: Patient Rated Outcome Measure (PROM).....	116
Appendix M: Social Stories™ Project; Semi-Structured Interview Schedule.....	117
Appendix N: Detailed outline of the study procedure .....	118
Appendix O: Participant Information and Consent Form .....	120
Appendix P: Carer Information Sheet.....	125
Appendix Q: Carer Consent Form .....	129
Appendix R: Functional analysis .....	130
Appendix S: Section of Transcript and IPA analysis .....	131
Appendix T: Ethical Approval Correspondence .....	132
Appendix U: Sarah’s Social Story .....	147
Appendix V: Chronology of Research Process .....	148
Appendix W: Guidelines to authors for target journal .....	150

Addenda A: Participant and carer interview transcript (submitted on an accompanying disc)



## LIST OF TABLES

### In Report:

Table 1. Project aims and methods of measuring .....	45
Table 2. Mean frequency of behaviours during each phase .....	49
Table 3. Table of IPA Themes.....	54

### In Appendices:

Table 1. Meta-ethnography phases taken from Noblit and Hare (1988) and corresponding sections of this paper .....	97
Table 2. Database Searches .....	98
Table 3. Summary of shortlisted articles that were quality appraised .....	99
Table 4.1 Sample, Methodology and Key Themes of articles synthesised in meta- ethnography.....	106
Table 4.2 Sample, Methodology and Key Themes of articles synthesised in meta- ethnography continued .....	107
Table 4.3 Sample, Methodology and Key Themes of articles synthesised in meta- ethnography continued .....	109

## **LIST OF FIGURES**

Figure 1. Frequency of the total undesired and appropriate behaviours over the phases of the study.....	50
Figure 2. Thematic Map for Sarah’s interview.....	51
Figure 3. Thematic Map for Michelle’s Interview.....	52

# **Literature Review**

**Being a “family with autism”:  
a meta-ethnography of qualitative  
research exploring families’ experiences of  
having a family member with autism.**

## 1. ABSTRACT

Research suggests that the parents of children with Autism Spectrum Disorders (ASD) experience more stress than parents of typically developing children and children with other developmental disabilities (Hayes & Watson, 2013). However existing quantitative research tells us little about the factors which are stressful or the experience of having a child with ASD. This meta-ethnography asked 'How do family members of an individual with an autism spectrum disorder make sense of their experience?'. Meta-ethnography is a method which synthesises qualitative research across papers to create a more in-depth understanding. Reciprocal translations were used to draw together and synthesis the themes that were shared across the papers. Nine qualitative papers were synthesised, these included three papers about parent experience (Hines *et al.*, 2014; Myers *et al.*, 2009; Woodgate *et al.*, 2008), four papers about sibling experience (Mascha & Boucher, 2006; Petalas *et al.*, 2009; Petalas *et al.*, 2012; Tozer *et al.*, 2013), one paper about grandparent experience (Margetts *et al.*, 2006) and one paper about family experience (DeGrace, 2004). A range of different family members' experiences were sought as the family is the system that wraps around the individual with autism. The following eight themes were synthesised; autism is not our relative, family life revolves around autism, the stress and strain of being a family with autism, tolerating that autism can bring aggression, families' accepting and seeking to understand autism, families' celebrate their relative's achievements and cherish happy moments, feeling judged and isolated by others, and fighting an inaccessible system. These themes provided further insight into families' experiences and were considered in relation to an existing model of parental stress (Deater-Deckard, 1998). It was recommended that more qualitative research needs to be conducted in the UK, particularly with parents about their experiences.

## 2. INTRODUCTION

Autistic Spectrum Disorder (ASD) is a developmental disability which spans a spectrum of difficulties around social communication, language development and repetitive behaviours. Autism is at one end of the spectrum where difficulties are more pronounced (National Institute for Health and Clinical Excellence, 2012). Throughout this paper the terms autism and the abbreviation ASD will be used to cover all disorders within the spectrum, unless otherwise specified.

The reported prevalence of ASD has increased in recent decades, which is an important factor to consider when providing services for this group of people (Baron-Cohen *et al.*, 2009; Morgan *et al.*, 2002; Wing & Potter, 2002). Wing and Potter (2002) listed 39 papers which had given prevalence rates of ASD in children, some as high as 60 per 10000 children. They discussed possible reasons for the increased prevalence and concluded that evidence suggested changes in the diagnostic criteria and an increase in awareness and therefore diagnosis were the most likely reasons for the increasing prevalence statistics (Wing & Potter, 2002). Research has suggested that the prevalence for children with ASD is approximately 1%, although this is likely to be a conservative estimate (Baird *et al.*, 2006). Morgan *et al.* (2002) noted that most prevalence studies focused on rates of diagnosis within populations of children. Their research focused on adults in a particular area of the UK who had contact with the learning disability services. They found that 30% of adults with a learning disability also met the criteria for having an autistic disorder, with higher prevalence rates in more intensive care settings (Morgan *et al.*, 2002). In 2009 the NHS Information Centre released a report which stated that the prevalence of adults with ASD was 1% in England. Some researchers have further suggested that ASD is a spectrum and it is likely that all people across the population have some traits which might fall along the spectrum (Baron-Cohen *et al.*, 2001; Baron-Cohen *et al.*, 2009; Scott *et al.*, 2002).

With the increased recognition and diagnosis of ASD, clinicians and researchers are highlighting the need for increased awareness of those caring for individuals with ASD (Bloch & Weinstein, 2010; Cadman *et al.*, 2012; James, 2013). Families can provide valuable support and care and therefore are a valuable resource for their relative and

community services (James, 2013). Government legislation and strategy emphasises that families should be consulted in the assessment of their family member's needs, have the right to an assessment for support from their local social services and that their caring responsibilities should be acknowledged (Department of Health, 2008; 2010; 2013).

There are numerous studies which suggest that parents of children with ASD experience high levels of stress (Hayes & Watson, 2013; Tehee *et al.*, 2009). It is important to understand the causes of stress and the impact of stress on families so that appropriate support and intervention can be put into place to reduce the negative impact stress can have and improve family functioning (Bloch & Weinstein, 2010; Hayes & Watson, 2013). Deater-Deckard (1998) defines parenting stress as "the aversive psychological reaction to the demands of being a parent". He proposed a model of parenting stress in which the child and the parent's social role as a parent are causal factors of stress. The parent's appraisal of the causes of the child's difficulties are key; the more the child's difficulties are perceived as within the control of the child, the greater the parenting stress reaction. The parent's adaptive coping mechanisms are important in not only reducing their own stress but also the impact this has on the child-parent relationship. He states that parenting stress can have a detrimental impact on a parent's psychological well-being (Deater-Deckard, 1998).

Researchers have attempted to quantify parenting stress using a variety of measures, although it has been argued that parenting stress cannot be assessed by a single measure as the experience of stress is a complex interaction between several factors (Deater-Deckard, 1998). Hayes and Watson (2013) conducted a meta-analysis of fifteen quantitative studies looking at parenting stress. They found that research does show that parents of children with ASD experience significantly more stress than parents of typically developing children and children with other disabilities. However they acknowledge that finding a significant difference in stress does not tell us why these parents experience more stress (Hayes & Watson, 2013).

Quantitative research has explored the difference between parents of children with ASD and other developmental disabilities or typically developing children. It has looked

at ideas around stress and coping; constructs which are derived from the researchers pre-conceived ideas of what factors might be impacted upon by having a child with ASD. However quantitative methods cannot tell us in what way their family experience is different and what are the things that contribute to the stress or ability to cope (Hayes & Watson, 2013; Myers *et al.*, 2009). It is important to also use qualitative methods of exploring experience, so that researchers and clinicians can achieve a deeper understanding of the lived experience of families (Bölte, 2014). Qualitative research can help us to understand the meaning people make from their experiences. Frankl (1984) suggested that the meaning people make from adverse events helps them to survive. Making positive meaning of disability is an important process in developing resilience, which is described as the ability to withstand adversity (Bayat, 2007). Therefore understanding the meaning families make of their lives is a crucial part of understanding the difficulties they face and the ways in which they are able to withstand these.

The present paper aims to explore and synthesise existing qualitative research on families' experience of having a family member with ASD. The present study uses the method of meta-ethnography, which seeks to analyse qualitative research and make new interpretations (Noblit & Hare, 1988). The question posed for this meta-ethnography is: How do family members of an individual with an autism spectrum disorder make sense of their experience?

### **3. METHOD**

#### **3.1 Epistemological stance**

The understanding of whether there is an ultimate "truth" and how we construct our knowledge influences the methodology researchers use and how they interpret their findings (Barnett-Page & Thomas, 2009). Therefore it makes sense to explain this researcher's epistemological stance first, so that the subsequent methodology can be understood within this context. The phrase often used in psychology literature to encapsulate the epistemological stance that the researcher takes is that of 'critical realism' (Barnett-Page & Thomas, 2009). See Appendix A for a more detailed explanation of epistemology and method selection.

### **3.2 Meta-ethnography**

A number of methods of qualitative research synthesis were considered. Noblit and Hare's (1988) meta-ethnography was felt to be the most appropriate (please see Appendix A for a full explanation). Meta-ethnography is a method which synthesises existing qualitative research in order to deepen the understanding of human experience and the way it is constructed. The synthesis seeks to draw together qualitative research concerning an area and through across study analysis explore whether the data taken together provides a deeper understanding. Meta-ethnography follows seven phases, which include literature searching, analysis and synthesis of data. The method and results sections are structured in a way which follows these phases (as outlined in Appendix B).

### **3.3 Literature Searching**

Initial scoping literature searches were conducted using PsychINFO and Scopus to examine the availability of research in relation to family experiences of a family member with ASD and to ascertain if a qualitative literature review or synthesis had already been undertaken. It was noted that there was a moderate amount of research pertaining to family experiences, some of which was related to experiences around diagnosis, particular interventions and service provision. No previous literature review or meta-synthesis in this area was found.

The search terms selected were 'Autism', 'famil\*' and 'experience' (see Appendix C for full explanation). Noblit and Hare (1988) comment on the importance of an exhaustive literature search and the use of an iterative process to narrow down relevant literature. Three databases were searched (PsychINFO, Scopus and Medline), ensuring that a wide range of psychological, educational and medical literature was searched. Literature was limited to those articles published in peer reviewed journals in the last ten years (from 2004 onwards) so that literature was of a good standard and relatively recent. The literature search was conducted in August 2014.

A total of 1091 articles were generated by the search. As Noblit and Hare (1988) emphasised using iterative processes to select relevant literature, rigorous inclusion and exclusion criteria were not applied initially. Literature was first screened by



reading the article title and abstract. Articles which appeared to have used qualitative methods to investigate family member's experience of their relative with ASD were short listed. Articles which clearly looked at experience of diagnosis, a particular intervention or service or hopes for the future were excluded. This was because the scoping literature search highlighted a moderate amount of literature relevant to the question and therefore topics which were somewhat but not directly related were excluded. A total of 63 articles were shortlisted, leaving 41 after duplicates were removed (see Appendix C).

These 41 articles were further narrowed down through reading the whole article to see if it did qualitatively investigate the general experiences of families with a family member with ASD as it had appeared to from the title and abstract. Of the 41 articles one article was excluded as it presented the same research as another article and had the same authors and 29 articles were excluded as on closer examination they were focused on more specific areas, such as intervention. Articles that looked at both general experience and more specific areas were also excluded, as extraction of the relevant area would have been necessary. The remaining 11 articles (see Appendix D) were quality appraised using an adapted quality appraisal tool created specifically for this review (please see Appendix E for a full explanation, Appendix F for a copy of the tool and Appendix G for a summary of the quality appraisal findings). The reference lists were also manually searched for any further relevant literature and one article was found and quality appraised. Following quality appraisal, one article was excluded as no specific qualitative analysis was undertaken. A further two papers were excluded as interviews were translated from the participant's native language into English, which may have resulted in some of the meaning being lost (Mouzourou *et al.*, 2011). This left nine papers which were included in the meta-ethnography.

### **3.4 Data extraction and analysis**

The nine papers were read multiple times so that the researcher became familiar with the contents. A data extraction form was used to pull out key pieces of information, themes and metaphors (please see Appendix H). There were a number of themes that were present in many of the articles and so reciprocal translations were undertaken. Reciprocal translations involve pulling together the shared meaning across many

qualitative accounts of experience and using the metaphors and words from particular accounts that seem to best embody the shared experience across accounts. Sometimes existing words in the accounts seem to communicate the shared experience, sometimes the analyst may use their own words to summarise the themes across articles (Noblit & Hare, 1988). Noblit and Hare (1988) advocated that metaphors and themes would sometimes use the words of existing articles where it was felt that these words best described and communicated the experiences being summarised and at other times new ways of wording these ideas could be created to fully communicate meaning.

#### **4. RESULTS**

Nine articles which qualitatively explored family members' experiences of having a son, daughter, brother, sister or grandchild with ASD were synthesised. Three articles looked at parental experiences; two used in-depth interviews (Hines *et al.*, 2014; Woodgate *et al.*, 2008) and one used an open question on an internet survey (Myers *et al.*, 2009). A further four articles used semi-structured interviews to explore sibling experience; three interviewed children and adolescents ranging from 9 years to 18 years (Mascha & Boucher, 2006; Petalas *et al.*, 2009; Petalas *et al.*, 2012) and one interviewed adult siblings aged 25 years to 67 years (Tozer *et al.*, 2013). One article interviewed families consisting of both parents and two children (DeGrace, 2004) and one article used semi-structured interviews to explore grandparent experience (Margetts *et al.*, 2006). All articles used qualitative analysis including phenomenological analysis (DeGrace, 2004), structural and thematic analysis (Hines *et al.*, 2014), inductive analysis (Margetts *et al.*, 2006), content analysis (Mascha & Boucher, 2006; Myers *et al.*, 2009), interpretative phenomenological analysis (Petalas *et al.*, 2009; Petalas *et al.*, 2012), narrative analysis (Tozer *et al.*, 2013) and the selective highlighting approach (Woodgate *et al.*, 2008).

Reciprocal translations were used to synthesise the following eight themes; *autism is not our relative, family life revolves around autism, the stress and strain of being a family with autism, tolerating that autism can bring aggression, families' accepting and seeking to understand autism, families' celebrate their relative's achievements and*

*cherish happy moments, feeling judged and isolated by others, and fighting an inaccessible system.*

For the purposes of clarity, double quotation marks indicate direct participant quotes as reported in the articles and single quotation marks indicate the article author's words. This distinction is made so that the connection with participant experience is maintained through direct use of their words.

#### *Autism is not our relative*

DeGrace (2004) referred to autism as 'an entity of its own' (pp.545). This idea seemed to appear implicitly across the other articles; it was not explicitly stated, but the use of language by participants suggested that this idea was shared by other families.

Language such as identifying the individual by name, or as 'son' or 'daughter' with no mention of them being autistic (Hines *et al.*, 2014; Margetts *et al.*, 2006; Myers *et al.*, 2009; Petalas *et al.*, 2012). Some parents used endearing terms of reference to their child (Myers *et al.*, 2009) and one sibling referred to his family as "a family with autism" (Petalas *et al.*, 2009, pp.388). The way language was used by the families of those with ASD strongly suggested that families perceived their relative as a person in their own right and that the ASD was a separate 'entity'. In fact one sibling states "I just recognise him as just another human" (Petalas *et al.*, 2009, pp389). This seems an important notion as it suggests that families do not blame the individuals with ASD and perhaps viewed the daily challenges they faced as battles against ASD and not the child. However this was not an idea that all family members seemed to share. For example some siblings referred to their sibling as their "autistic sibling" (Tozer *et al.*, 2013, pp.483) or stated "he's autistic" (Mascha & Boucher, 2006, pp.23) and one parent referred to his son as "the boy" who he suggested was to blame for his heart attack (Hines *et al.*, 2014, pp.169).

#### *Family life revolves around autism*

The idea of 'family life revolves around autism' hints at the power autism had within families. DeGrace (2004) used the theme 'whole family life revolves around autism' and this felt like it really connected with the experiences described by many of the relatives across the papers. Parents explicitly stated this; "your whole family's life is

always revolving around this situation” (DeGrace, 2004, pp.546), “our entire lives revolve around autism” (Myers *et al.*, 2009, pp.679) and adult siblings also echoed this when they described that home life had “revolved around autism” (Tozer *et al.*, 2013, pp.438). Parents described living ‘regimented’ lives due to the routines they felt their child needed (Hines *et al.*, 2014, pp.168) and that they were “ruled by his fixations” (Myers *et al.*, 2009, pp.675). Grandparents also suggested that that their lives also revolved around autism; “I was available for them 7 days a week” (pp.569) and “We frequently get calls late at night especially with [grandson] and I’ll go” (Margetts *et al.*, 2006, pp.670). In some accounts life revolving around autism restricted the activities the families could share together; “there are some things that we do not even attempt” (Myers *et al.*, 2009, pp.680) and “we’d rather do a lot more” (DeGrace, 2004, pp.547). Interestingly this theme was not noted in the three accounts of child siblings, who perhaps had known nothing else in their family life and therefore had a different perception.

#### *The stress and strain of being a family with autism*

All but two of the child sibling accounts labelled themes which resonated with the idea of the stress and strain families felt under. The word stress was one commonly used in accounts to describe parent’s feelings; “the stress is constant” (Myers *et al.*, 2009, pp.674) and ‘accrued stress’ that “just constantly builds up” (DeGrace, 2004, pp.546). Parents described feeling ‘exhaustion’; “we are always tired” (Myers *et al.*, 2009, pp.676) and that they had no ‘time away from autism’ (DeGrace, 2004, pp.547). One article about child sibling experiences highlighted the emotional impact having a sibling with autism had; “it can affect me” and siblings felt “irritated” and “angry” (Petalas *et al.*, 2009, pp.387).

Parents talked of the “burden of trying to do the right things by the other kids as well” (Hines *et al.*, 2014, pp.168) and the authors described this as a ‘balancing act’ and that families ‘trod a fine line’. Some talked about “working towards a healthy balance” (Woodgate *et al.*, 2008, pp.1080) and Hines *et al.* (2014) stated a ‘family’s survival depend on the degree to which families are able to maintain balance’ (pp.167). Parents stated that siblings “get the short end of the stick” and had to “stand in line for their needs” (Myers *et al.*, 2009, pp.679). Adult siblings talked about feeling “guilty” around

balancing their different commitments with their sibling relationship (Tozer *et al.*, 2013, pp.485). Grandparents also felt strain; “I must look out for all the family” (pp.571) and worried about all members of the family; “our worries were not just for our [granddaughter], but also for [son] and [daughter-in-law]” (Margetts *et al.*, 2006, pp.569). Some parents noted the impact on their own marriage; the “marriage is strained”, they had “no time together” and “no privacy” (Myers *et al.*, 2009, pp.677). Many talked about the financial impact; it’s “ruined us financially”, although some also stating “it was worth every penny” (Myers *et al.*, 2009, pp.679).

#### *Tolerating that autism can bring aggression*

This theme was highlighted in all three child sibling accounts of their experience of having a sibling with autism. The word “violent” (Petalas *et al.*, 2012, pp.307) was used to describe their sibling in one account. Behaviour described in other accounts included; “he just chucks things at you, shouts at you, screams at you”, “he hits me, or throws something at me, or calls me names” (Petalas *et al.*, 2009, pp.387) and “she gets angry” (Mascha & Boucher, 2006, pp.22). This aggression was also mentioned in some parent accounts; there were “tantrums and screaming”, “aggression” and “she can become violent” (Myers *et al.*, 2009, pp.676).

#### *Families’ accepting and seeking to understand autism*

Across grandparents, parents and siblings there were ideas that resonated with the theme of understanding and acceptance, in spite of all the difficulties. There were declarations of love from parents; “I love him no matter what’s wrong” (Myers *et al.*, 2009, pp.679); siblings: “you love him to bits” (Tozer *et al.*, 2013, pp.484); and grandparents: “I love him best of all” (Margetts *et al.*, 2006, pp.569). These declarations suggest that that regardless of difficulties they accept and love their relative with autism. Siblings accepted their sibling; “I like him the way he is” (Petalas *et al.*, 2009, pp.390) and “it’s kind of cool that he’s different” (Petalas *et al.*, 2012, pp.309). Siblings indicated their understanding of their sibling with autism through statements explaining their odd behaviour; “something in there making them do it” (Petalas *et al.*, 2012, pp.307). They also talked about how understanding their sibling made things easier; “my parents spent a lot of time telling me about it....it made it a lot easier to understand why” (Mascha & Boucher, 2006, pp.23). Grandparents

acknowledged that it was difficult to 'tolerate' not knowing the cause of autism (Margetts *et al.*, 2006, pp.571). However acceptance was not a completely shared experience, one sibling stated "I'd make him a normal person" (Petalas *et al.*, 2009, pp.390) and "If I had a magic wand, I'd take away the autism" (Petalas *et al.*, 2012, pp.309).

#### *Families' celebrate their relative's achievements and cherish happy moments*

This theme was strongest in the sibling accounts, possibly because they were often asked to talk about the good things about having a sibling with autism. They talked about their sibling's positive qualities; "he's really nice sometimes; he's really fun" (Petalas *et al.*, 2009, pp.390), having "fun" and "spending lots of time together" (Petalas *et al.*, 2012, pp.308; Mascha & Boucher, 2006). Parents mentioned 'fleeting moments' of "feeling like a family" (DeGrace, 2004, pp.547). They also talked of their experiences having "made our family stronger" (Myers *et al.*, 2009, pp.680).

There was admiration and pride in relation to the achievements the family member with autism had made. Siblings commented "he like knows absolutely more than me" (pp.390), "he's good at remembering things" (pp.391), "he won a computer by doing horse riding.... I was really pleased" (Petalas *et al.*, 2009, pp.391) and "he's really quite remarkable" (Petalas *et al.*, 2012, pp.310). Woodgate *et al.*, (2008) created the theme 'cherishing different milestones' (pp.1080) and parents acknowledged achievements; "everyday is a new accomplishment" (Myers *et al.*, 2009, pp.678).

#### *Feeling judged and isolated by others*

Parents and siblings were aware of what others' thought about their child/sibling. These judgements came not only from strangers but their friends and extended family as well. Parents reported that "strangers stare", "others have made fun of my son, both adults and children" and "I have heard all the remarks, I have sensed the animosity from acquaintances and strangers" (Myers *et al.*, 2009, pp.681). Siblings noted that others "don't see [sibling] for who he really is" (Petalas *et al.*, 2009, pp.388) and that "they just don't understand" (Petalas *et al.*, 2012, pp.308). It was difficult "trying to explain what his problem is" (Mascha & Boucher, 2006, pp.23). Much of the time parents and siblings felt embarrassed (Mascha & Boucher, 2006; Myers *et al.*,

2009; Petalas *et al.*, 2009; Petalas *et al.*, 2012). Some siblings had found ways to manage this judgement; “you pretend no-one’s looking” (Petalas *et al.*, 2012, pp.308), “you tell them more about it” or you “don’t really speak about it” (Petalas *et al.*, 2009, pp.388). Some parents had ‘stopped minding’ so that it didn’t “bother me anymore” (Myers *et al.*, 2009, pp.681).

Parents in particular found that they felt ‘isolated’ from extended family members who ‘seemed to lack an essential understanding of what they were going through’ (Woodgate *et al.*, 2008, pp.1078). In some cases parents have felt blamed for their child’s difficulties by relatives who expressed that they “were inadequate parents” and “made it clear that they believe that I caused my son’s autism” (Myers *et al.*, 2009, pp.680). They had “lost most of our friends” (Myers *et al.*, 2009, pp.681) and had “missed out” on social events (Hines *et al.*, 2014, pp.168). In some cases judgement also came from teachers, one parent stated “the school is stigmatizing my son” (Woodgate *et al.*, 2008, pp.1078).

It seemed fairly common that family lives revolving around autism resulted in the restriction of family activities and further compounded the isolation they felt; “we go nowhere, or do anything social. Church is even a difficult outing” (Myers *et al.*, 2009, pp.681), “we have no life” (Woodgate *et al.*, 2008, pp.1078).

### Fighting an inaccessible system

All three articles that explored parent’s experiences spoke of their ‘fight’ with services and siblings were also aware of this. Parents talked of their ‘anger and frustration’ with schools and services (Myers *et al.*, 2009, pp.676), and expressed negative attitudes towards services, no doubt as a result of their experiences; “we can not let the system rip them off” (Woodgate *et al.*, 2008, pp.1081) and “they will mow us down” (Hines *et al.*, 2014, pp.170). In Woodgate *et al.* (2008) the “system” is described as ‘a conglomerate of all child-related agencies and institutions’ (pp.1078) and ‘inaccessible in many ways’ (pp.1079). This seemed to translate into the reported experiences of other parents. The word ‘fight’ was commonly used to describe their interactions with services; “I have fought them tooth and nail” (Hines *et al.*, 2014, pp.170), “we have had to fight for everything we’ve gotten for him” (Myers *et al.*, 2009, pp.676), “fighting all

the way” (Woodgate *et al.*, 2008, pp.1081). Child siblings had observed that their parents had to “battle” with services (Petalas *et al.*, 2012, pp.307). Adult siblings reported that when they were children “professionals weren’t really interested” in them, as adults they sometimes felt ‘judged by staff’ and ‘wanted to be supported in whatever role they chose to adopt’ (Tozer *et al.*, 2013, pp.845).

## 5. DISCUSSION

The present paper aimed to synthesise existing qualitative research on families’ experience of having a family member with ASD. The question asked was: How do family members of an individual with an autism spectrum disorder make sense of their experience? Making meaning from their experience was thought to help them withstand the difficulties they faced (Bayat, 2007; Frankl, 1984). Existing research has tended to focus on just one group of people, for example parents or siblings. However, this meta-ethnography pulls together the experiences of different family members; grandparents, parents and siblings. The researcher considered this to be important as the family is the system around the individual with ASD and was interested in the extent to which they shared similar experiences. Noblit and Hare’s (1988) meta-ethnography approach was used and eight themes of experience were identified through the nine articles using reciprocal translations. These eight themes were; *autism is not our relative, family life revolves around autism, the stress and strain of being a family with autism, tolerating that autism can bring aggression, families’ accepting and seeking to understand autism, families’ celebrate their relative’s achievements and cherish happy moments, feeling judged and isolated by others, and fighting an inaccessible system.*

This synthesis found that different family members did indeed share similar experiences and none of the themes were exclusive to any group of family members, although some themes seemed to be more strongly voiced by certain groups. For example the themes of *tolerating that autism can bring aggression* and *families celebrate their relative’s achievements and cherish happy moments* were present in all the child sibling articles. This may have been as the researchers asked questions around the positives and negatives of having a sibling with autism and therefore



guided the information they yielded. Some themes were more strongly voiced by parents, such as *family life revolves around autism* and *fighting an inaccessible system*. The theme of *family life revolves around autism* was not present in the child sibling accounts and this may have been as they had known no other family life and therefore it seemed 'normal' to them. It was noted in the adult sibling experiences and it could be suggested that time away from the family home made this experience evident for them. The theme of *fighting an inaccessible system* was an action that took up a lot of time for parents and something that child siblings had no involvement in but some had an awareness that this was happening.

These themes tell us more in-depth information about how families understand ASD, the difficulties they face and the ways in which they survive their battles with ASD. The theme of *autism is not our relative* encapsulates the idea that autism is not considered to be an individual's identity, but a separate condition which imposes behaviours and ways of doing things on the individual, and as a result *family life revolves around autism*. These families were not only restricted in their leisure activities by what the child could tolerate, but also by *feeling judged and isolated by others*. The stares and comments from strangers, friends and relatives left families feeling that they were unwelcome in the company of others. It is also possible that their experiences of being judged also led them to withdraw to avoid the embarrassment they so often felt. Friends and family often did not understand the stress and strain the families were under and their constant battles in *fighting an inaccessible system*. Despite the difficulties these families faced, they continued to strive for a balance in their lives which was thought to be a crucial part of surviving. The idea of *families' accepting and seeking to understand autism* also seemed to be an important part of withstanding the difficulties they faced. They felt love for their family member, pride and admiration at what they were good at and celebrated these achievements. It seemed that the theme of *families' celebrate their relative's achievements and cherish happy moments* also helped families to continue to withstand the difficulties they faced and continue to battle for the needs of their loved one.

Quantitative research tells us that parents of children with ASD experience significantly more stress than parents of typically developing children and children with other

disabilities (Hayes & Watson, 2013). The eight themes generated by the meta-ethnography provide rich information about what stresses these families face. Six of the eight themes hold negative connotations; *autism is not our relative, family life revolves around autism, the stress and strain of being a family with autism, tolerating that autism can bring aggression, feeling judged and isolated by others, and fighting an inaccessible system*. These themes help us understand in greater detail the factors which make life so stressful for these families.

This meta-ethnography provides some support for Deater-Deckard's (1998) model of parenting stress, but also highlights additional factors that have not been taken into account. It is important to note that Deater-Deckard's model is of parenting stress, but this meta-ethnography has taken into account the whole family's experiences and so these suggestions should be treated with caution. The model proposed that some parental stress arises from the social care-giver role that the parent takes on, with its accompanying social expectations (for example, devoting time to child-rearing) (Deater-Deckard, 1998). The themes yielded in this paper provide some support for this, for example the theme of *the stress and strain of being a family with autism* highlights the parental struggle to take care of all of their children well when their child with ASD requires more support. It could be argued that parents try and achieve this balance due to the social expectation that they must care for their children equally. The theme of *feeling judged and isolated by others* also highlights the way in which social expectations impact on parental stress. It encapsulates parental experiences of feeling judged or blamed for the child's difficulties, which led to social isolation. Parents seemed to fully take on the responsibilities of their parent role, which was evident in the theme *fighting an inaccessible system*. This showed that they tried to do everything they could to ensure that their child's needs were met, to the extent that it was the centre of their lives (as reflected in the theme *family life revolves around autism*).

The model also suggests that parental stress arises from the child itself and is increased when parents believe the child is in control of their behaviour (Deater-Deckard, 1998). This idea does not seem to be supported by the themes found in this paper. In fact the family accounts of their experiences suggest that they did not blame

the child for their difficulties, as reflected in the themes *autism is not our relative* and *families' accepting and seeking to understand autism*. These themes describe the shared sense that autism was a difficulty separate to the child and as such, not their fault. The theme of *families' accepting and seeking to understand autism* shows us that families understood the individual's challenging behaviour and that this understanding helped make things easier for them. Bayat (2007) and Frankl (1984) suggest that the way in which people make meaning from their experiences helps them to cope with difficulties. Deater-Deckard (1998) suggested that parenting stress is alleviated by adequate coping mechanisms. For the families of individuals with ASD, perhaps this way of making sense of ASD as something separate from their child, helped to reduce the stress they might have felt if they believed their child was in control of their difficulties. The themes revealed in this meta-ethnography also give some indication of the positive experiences and meanings the families made, which may have acted to strengthen their resilience. The themes of *families accepting and seeking to understand autism* and *families' celebrate their relative's achievements and cherish happy moments* show us that understanding the individual with autism made it easier to live with them and that the celebration of their individuality, strengths and achievements was an important part of acknowledging them as a person.

Government legislation and strategy is now starting to take into account the valuable caring role that families provide for individuals with ASD (Department of Health, 2008; 2010; 2013). This meta-ethnography is useful as it provides details about the difficulties faced by families and the ways they make meaning to help them survive. This is really important when thinking about what support families might benefit from. The theme of *fighting an inaccessible system* is a worrying one for service providers. It is important to note that the articles exploring parental experience that were included in the meta-ethnography were conducted in the United States of America (DeGrace, 2004; Myers *et al.*, 2009), Canada (Woodgate *et al.*, 2008) and Australia (Hines *et al.*, 2014). Interestingly the literature search used in this paper did not find any research conducted in the UK regarding general parent experience of having a child with ASD. A number of articles which focused on service provision were excluded, however none of these were conducted in the UK. All sibling and grandparent experience research

included in this meta-ethnography was conducted in the UK. There were sibling accounts of them recognising their parent's difficulties with services, which suggested that the theme *fighting an inaccessible system* still has some relevance in the UK. It is clear that more research needs to be conducted with parents in the UK. Services may need to consider the barriers that make it difficult for parents to seek the support they need and whether the support available meets these families' needs.

A further area of interest for services is that understanding their child's behaviour helps them to live with it. Services could provide more support in helping parents make sense of the behaviour and the difficulties that characterise autism. It might also be important for professionals to have an awareness that their intervention may be contributing to family life revolving around autism and that should be considered with families. For example DeGrace (2004) reflected that interventions should support meaningful shared activities for the family, rather than focus on controlling behaviour.

There are limitations of this paper and the method of meta-ethnography. The nature of qualitative research is such that it requires interpretation. Interpretation is done through the lens of the researcher and the influence of their own world views can never be removed. In the method of qualitative research and then meta-ethnography a number of different people have made interpretations. In this paper three layers of interpretation have taken place, thus there is a triple hermeneutic. The participant has interpreted their experience and voiced this in their interaction with the researcher, the researcher has interpreted their experience and created themes and the method of meta-ethnography done by this researcher has added another layer of interpretation. These multiple layers of interpretation may have led to the essence of people's experiences being lost or distorted. A number of the papers included in this meta-ethnography took measures to avoid this, such as feeding back their analysis to their sample, multiple researchers checking the analysis against the data and keeping reflective diaries (further details can be found in Appendix G where the quality appraisal findings are summarised).

The findings of this paper highlight that family experiences of having a family member with autism are complex. This paper attempted to draw themes of experience through

the meta-ethnography approach, but it important to note that not all accounts fitted with the themes identified. As with any area of human experience, each individual has a unique experience and perspective.

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# **Research Report**

**Using a Social Story™ with an adult  
diagnosed with a Learning Disability and  
Autism Spectrum Disorder:**

**A qualitative analysis of a mother and  
daughter's experience**

## 1. ABSTRACT

The National Institute for Health and Clinical Excellence (NICE; 2012, 2014) make recommendations for age appropriate psycho-social interventions to support those with Autism Spectrum Disorders (ASD). However there are few evidence based interventions recommended. Social Stories™ have received a lot of interest as an intervention which provides contextual information to help those with ASD understand the world around them (Gray & Garand, 1993, Gray, 2010). Originally designed for children with Autism, clinicians have begun using them with adults with ASD, however the evidence base is limited. This paper presents a single case study of an adult with a Learning Disability and ASD, and their carer's experience of using a Social Story™ as a structured intervention. Quantitative behaviour monitoring demonstrated a reduction in behaviours viewed as problematic in the situation targeted by the Social Story™. Qualitative data was gathered in a joint semi-structured interview and was analysed using Thematic Analysis and Interpretative Phenomenological Analysis (IPA). Thematic Analysis highlighted themes related to the cognitive behavioural theories underpinning the Social Story™; that the story supported understanding and information processing, reduced participant distress and helped the carer to have a greater understanding of her daughter's difficulties processing information. The IPA highlighted the relational processes that seemed to be occurring through the use of the story. All themes resonated with the over-arching theme of 'need to contain separation anxiety', and suggested that the story supported the process of separation and strengthened the parent-child relationship. Therefore, the Social Story™ was interpreted as acting as a 'transitional object', according to Winnicott's definition of the term (Winnicott, 1953). The implications of a relational understanding are discussed, along with how this intervention may need to be adapted for adults with ASD, the limitations of the study and avenues for further research.

## **2. INTRODUCTION**

Learning Disabilities are defined as “a significantly reduced ability to understand new or complex information and to learn new skills, coupled with a significantly reduced ability to cope independently” (Department of Health, 2001). Autistic Spectrum Disorders (ASD) are developmental disabilities which span a spectrum of difficulties around social communication, language development and repetitive behaviours. Autism is at one end of the spectrum where difficulties are more pronounced (NICE, 2012). Throughout this paper the abbreviation ASD will be used to cover all disorders within the spectrum, including autism. Appendix I offers a summary of some of the theories which attempt to explain the difficulties of individuals with ASD.

### **2.1 Prevalence of ASD and co-morbidity with Learning Disabilities**

Reported prevalence rates vary and seem to be more commonly reported for children than adults. The ASD prevalence rates in children could be as high as 60 per 10000 and this increase could be attributed to changes in the diagnostic criteria and an increased awareness and diagnosis (Wing & Potter, 2002). Amongst adults the prevalence rates are not so clear and it is suspected that there are many people with ASD that do not come into contact with services. The NHS Information Centre (2009) reported that the prevalence of adults with ASD was 1% in England. There is an established link between Learning Disabilities and Autistic Spectrum Disorders with high levels of co-morbidity (Wing & Gould, 1979). Morgan *et al.* (2002) looked at an area within the UK and found that 30% of adults with a learning disability also met the criteria for having an autistic disorder, with higher prevalence rates in more intensive care settings.

### **2.2 Current Guidelines and Recommendations**

With rising awareness and prevalence of ASD, there has been an increase in published strategies and guidelines for people with ASD. In 2009 the National Autistic Society (NAS) published a good practice guide for local authorities (NAS, 2009). As a result of The Autism Act in 2009, the Department of Health (DoH) produced a strategy for adults with autism. This outlined the government’s commitment to providing services for those with ASD to allow them to live as independently as possible and be supported to work and lead fulfilling lives (DoH, 2010). In 2012 NICE published

guidelines focused on recognition, diagnosis and management of autism. A section of these guidelines reviewed psychosocial interventions for those on the spectrum. They make a number of recommendations, including social learning programmes for social interactions and training programmes focused on life skills. NICE acknowledge that the evidence base is limited for effective interventions and recommend further research (NICE, 2012). These guidelines were reviewed in 2014 and no further updates were made at that time, suggesting that no further significant evidence base for interventions had been developed. In 2014 NICE published quality standards for autism, which states that people with autism should have discussions about what age appropriate psychosocial interventions are available to them to address the core features of autism. It also recommends that for those with challenging behaviour, a thorough assessment should be conducted to establish the cause, including physical and mental health, social and environmental factors (NICE, 2014). However there are still few recommended effective psychological and psychosocial interventions.

### **2.3 Social Stories™**

An intervention for those with ASD that is currently receiving a lot of interest is Gray's Social Stories™ (Gray & Garand, 1993; Gray, 2010). Social Stories™ are situation specific short stories which aim to provide contextual information about a situation to help an individual know what to expect and socially appropriate ways to manage the situation. These stories aim to reduce individual's distress through increasing their understanding, which may in turn reduce inappropriate behaviours, although this is not the primary aim (Gray, 2010). This intervention provides social information that the individual with ASD struggles to recognise and interpret due to their difficulties with social understanding (Ali & Frederickson, 2006). Social Stories™ were originally designed for children with ASD and have been successful in helping their inclusion in the classroom, adapting to new routines and teaching social skills (Gray & Garand, 1993).

Gray (2010) advocates that the stories should be carefully composed of seven types of sentences; descriptive, perspective, coaching of the recipient, coaching of the people around the recipient, self-coaching, affirmative and partial. These sentences help to describe the situation, what others might be doing or thinking, what they might be

able to do and what others could do to help. There are detailed guidelines for writing a Social Story™ to ensure that it maintains a respectful tone and that the story is emotionally and practically safe (Gray, 2010). Social Stories™ can include pictures and there are suggestions of more creative ways to present them, such as comic strips (Gray, 2010; Gray, 1998; Howley & Arnold, 2005).

#### **2.4 Evidence Base for the use of Social Stories™ with children (aged 3 to 12 years)**

Since Social Stories™ were first written about in 1993, there has been a wealth of research on their effectiveness as an intervention for children with ASD. Many of these studies are case studies which demonstrate the individually tailored intervention. Case studies are not considered to be very high on the hierarchy of evidence bases, however it can be argued that the nature of the intervention being evaluated is an individually tailored one and therefore case studies are the most appropriate method (Ali & Frederickson, 2006; Shadish, 2014).

In recent years a number of reviews of the evidence have been published, many of which highlight positive findings (Ali & Frederickson, 2006; Karkhaneh *et al.*, 2010; Styles, 2011). Ali and Frederickson (2006) reviewed 16 studies (including single case designs, multiple participant studies with single case designs and group evaluation) which found that all studies reported positive effects of Social Stories™. These included a reduction in tantrum behaviours such as hitting, screaming and throwing things and inappropriate social interactions. However some of those effects were only moderate and in some studies other interventions had also been used making it difficult to know what the positive changes were attributed to (Ali & Frederickson, 2006). Karkhaneh *et al.*, (2010) conducted a systematic review of six controlled trials using Social Stories™. Five of the six studies demonstrated statistically significant positive outcomes in relation to social interaction (Karkhaneh *et al.*, 2010). Styles (2011) reviewed 51 studies using Social Stories™ and concluded that although many studies reported positive findings there were still methodological flaws that prevented the evidence base from being strong enough to recommend Social Stories™ as a stand-alone evidence-based intervention.

Some reviews have reported mixed findings (Kokina & Kern, 2010; Reynhout & Carter, 2011; Test *et al.*, 2011). Kokina and Kern (2010) conducted a meta-analysis of 18 single case studies and concluded that Social Stories™ had a low efficacy rate. Reynhout and Carter (2011) conducted analysis of 62 Social Story™ studies using three small *n* metrics and concluded that Social Stories™ generally had a small clinical effect on behaviour. Test *et al.*, (2011) reported mixed findings, with some studies demonstrating effectiveness and others not.

## **2.5 Evidence Base for the use of Social Stories™ with adolescents and adults (aged 13 to 57 years)**

As the positive findings for children with ASD have been published, clinicians and researchers have begun to use Social Stories™ with adolescents and adults with various developmental disabilities. At the time of writing only five published papers for this group could be found (Bledsoe *et al.*, 2003; Bulcholz *et al.*, 2008; Graetz *et al.*, 2009; Samuels & Stansfield, 2012; Richter & Test, 2011). One paper is excluded from this summary of research with adolescents and adults, as the Social Stories™ were not tailored for each participant (which is usually how they are created). Therefore it is difficult to ascertain whether the intervention was really a Social Story™ (Richter & Test, 2011). The remaining four papers present a total of ten participants with diagnoses of ASD, Prader-Willi Syndrome, Downs Syndrome and Learning Disabilities. Ages ranged from 13 to 57 years.

All researchers used individual case studies with varying designs, including an ABAB design (Bledsoe *et al.*, 2003), an ABA design (Bulcholz *et al.*, 2008), an AB with generalisation and maintenance phases (Graetz *et al.*, 2009) and an AB with fade and follow-up phases (Samuels & Stansfield, 2012). For each participant, the Social Story™ targeted an identified behaviour which was monitored throughout the phases of the study. Nine of the participants demonstrated a reduction in the behaviour targeted by the Social Story™, suggesting that the Social Story™ was successful in supporting behavioural change (Bledsoe *et al.*, 2003; Bulcholz *et al.*, 2008; Graetz *et al.*, 2009; Samuels & Stansfield, 2012). For one of the adult participants there was little change following the implementation of the Social Story™ (Samuels & Stansfield, 2012). In addition some researchers noted that the Social Stories™ seemed to have a positive



impact on those around the participant. Bledsoe *et al.*, (2003) observed that the participant's peers were more likely to interact with the participant following the Social Story™ being implemented. Bucholz *et al.*, (2008) also noted that Social Stories™ had a positive effect not only on the participant receiving the intervention but also on their co-workers.

There are differences between some of the papers regarding how sustainable the behaviour change was, with some research finding that when the Social Story™ was removed the positive change was not maintained (Bledsoe *et al.*, 2003). However, some research found that the positive behaviour change was maintained at follow up (Bucholz *et al.*, 2008; Graetz *et al.*, 2009). Graetz *et al.*, (2009) also found that the inappropriate behaviours also decreased in other settings, suggesting that the participants had generalised their new learning to other situations.

## **2.6 Criticisms of Social Story™ Research**

Reviewers so far have raised a number of methodological criticisms of the research published to date. The use of single case studies has been repeatedly criticised due to a lack of control participants, not controlling for other variables, poor ecological validity and not being able to generalise the results (Ali & Frederickson, 2006; Karkhaneh *et al.*, 2010; Test *et al.*, 2011). Although there have been a great deal of criticisms of single case studies, Ali and Frederickson (2006) argue that the difficulties faced by each individual with ASD are complex and unique to them and therefore a personalised intervention, such as a Social Story™ is necessary. This individually tailored intervention requires individual outcomes and these do not lend themselves to larger experimental designs. They further noted that averaging results out over a group of participants limits evaluating the effectiveness of each individual's intervention (Ali & Frederickson, 2006).

There are specific guidelines for creating Social Stories™ and some researchers do not make it clear whether they have adhered to these (Bledsoe *et al.*, 2003; Bucholz *et al.*, 2008; Cihak, *et al.*, 2012). In some studies Social Stories™ have not been individually tailored for each participant as recommended (Richter & Test, 2011). This makes it difficult to ascertain whether they are really evaluating a Social Story™. It has also

been noted that in some studies Social Stories™ were provided in conjunction with other interventions, such as verbal prompting and role play, making it difficult to evaluate the effectiveness of just Social Stories™ (Styles, 2011; Test *et al.*, 2011).

## **2.7 Recommendations for Further Research**

Despite continued debate about the best way to assess Social Story™ effectiveness, further research continues to be advocated (Rust & Smith, 2006). Researchers have suggested a number of factors which increase the effectiveness of Social Stories™; these included targeting specific challenging behaviours, prior functional analysis of the behaviour and reading the story immediately prior to the targeted situation (Cihak *et al.*, 2012; Kokina & Kern, 2010). There are also some suggestions about the way Social Stories™ are implemented with adults being different to the way they are used with children. Samuels and Stansfield (2012) suggested that adults' behaviour is more embedded and therefore harder to change. They used a 'fade' stage where the intervention was gradually removed (Samuels & Stansfield, 2012). Therefore these factors should be considered when researching the effectiveness of Social Stories™.

The aim of Social Stories™ is to reduce the distress which arises when a situation is not understood by the individual and a reduction in challenging behaviour may be an additional benefit (Gray & Garand, 1993; Gray, 2010). However most studies look at the frequency of behaviour and do not appear to measure the client's distress. It is therefore suggested that future research includes measures of client distress regarding the situation the story is targeting. This could be a qualitative interview or observation about distress before and after the Social Story™. This would help to further evaluate the intended outcome of Social Stories™. In addition research has not investigated the participant and carers' experience of using a Social Story™. Exploring this may shed light on the psychological processes that impact on using a Social Story™.

## **2.8 Aim of this Research Paper**

This research paper asked *"What are the experiences of an adult diagnosed with a Learning Disability and Autism Spectrum Disorder, and their carer who have used a Social Story™?"*. This research aimed to explore the lived experience of using a Social Story™ intervention.

### **3. METHOD**

The original design aimed to collect interview data from a sample of N=4 adults with Learning Disabilities and ASD and their carers. It intended to use Thematic Analysis to identify useful themes from the data that would illuminate how the Social Stories™ were used. However there were problems with recruitment of an adequate sample for this, and the study was adapted to one that explored the experience of a single pair of adult and carer using Interpretative Phenomenological Analysis (IPA).

#### **3.1 Study Design**

Originally, this study used an individual case study design. Case studies are acknowledged as a good methodology in a heterogeneous population, allowing for participants to act as their own controls and for variation to be investigated rather than seen as a confounding factor (Ali & Frederickson, 2006). Furthermore, case studies allow for each participant's unique and complex difficulties to be addressed with a tailored Social Story™ intervention.

The case study followed an AB design with fade and maintenance stages. This design was chosen to avoid the ethical issues of withdrawing an intervention in an ABAB design (Ali & Frederickson, 2006). Additionally this design allowed extended time for the participant to learn and internalise the Social Story™, which was considered necessary as it has been suggested that adults' behaviour may be more embedded and take longer to change (Samuels & Stansfield, 2012). Specified behaviours were monitored throughout the stages of the study. A quantitative measure of participant distress about the target situation was used as Social Stories™ aim to reduce the recipient's distress in a situation (Gray & Garand, 1993; Gray, 2010). Previous research has focused solely on behaviour change and as this is not the primary goal of the intervention the researcher also wanted to explore participant distress. An interview was conducted at the end of the maintenance stage, with both the participant and carer to qualitatively explore their experience of the intervention. The interview notes were initially analysed using Braun and Clarke's (2006) Thematic Analysis. However, as only one adult and carer pair was recruited, the interview was then fully transcribed and re-analysed using IPA to explore, in a more in-depth way, the experience of the

participant and carer and the meaning they made of using a Social Story™ (Smith *et al.*, 2009). This was chosen as Thematic Analysis is suited to explore data from a larger sample of participants and extract themes that are pertinent across a population. IPA on the other hand, takes an idiographic stance taking each case and exploring it individually before potentially considering any other cases, and may also be applied to a single case.

### **3.2 Participants**

The research project was advertised to staff teams working in a Community Learning Disability Service in the Midlands region of England. Staff were asked to consider if they had any clients who met the criteria for the study and to seek consent from the service user and carer to be contacted about the study. Those who agreed to be contacted were referred to the study and then contacted by the researcher who further explained the study and arranged a meeting if the carer and service user were interested. The referral form, which also lists a checklist of the inclusion and exclusion criteria, can be found in Appendix J.

Ten service users were referred to the study; three consented to be involved, one did not consent and six were not eligible for the study; reasons for exclusion were three did not display the target behaviour frequently enough, one scored too highly on the HONOS, one's behaviour was not a simple behavioural problem and one had very limited communication and would have been unable to consent.

Of the three participants who consented to be involved, only one completed the research. This participant was 'Sarah' (names changed to protect confidentiality) who was a 26 year old woman with a visual impairment and diagnoses of a Learning Disability and ASD. Sarah lived at home with her mother ('Michelle') and brother, who also had Autism. She attended a range of supported groups in the community daily. She was referred for a Social Story™ related to her interactions with her mother.

### **3.3 Measures**

A range of measures were used including behaviour monitoring (of undesired and appropriate behaviours specific to each participant), a service Patient Rated Outcome Measure (PROM) and semi-structured interviews. These measures corresponded with

the original project aims as outlined in Table 1. The participant and carer were always seen in their home over the course of the study. They requested to be interviewed together at the end of the study which was facilitated to support their engagement. A semi-structured interview schedule was used to guide this interview. The interview schedule was designed to undertake Thematic Analysis. Therefore it was not created with the intention of undertaking phenomenological research and the limitations of this will be discussed in the discussion section.

Table 1. Project aims and methods of measuring

<b>Project Aim</b>	<b>Measure</b>
1. To investigate if Social Stories™ decrease undesired behaviours and increase appropriate behaviours	Undesired target behaviours and appropriate social behaviours were identified during the set up and the frequency of these behaviours was monitored throughout all phases. An individually tailored behaviour recording tally sheet was created (see Appendix K for a template).
2. To investigate if Social Stories™ reduce the participant's distress in a target situation.	This was measured using a PROM routinely used by the service (see Appendix L). The measure used a twelve point Likert scale to rate happiness with the goal agreed on (the target situation that the Social Story™ was directed at). The participant rated this before and after the intervention.
3. To assess whether the effects of the Social Story™ are maintained	Behaviour frequency was monitored through fade and maintenance phases.
4. To assess whether the information learned from the Social Story™ is generalised to other situations.	This was done qualitatively through post-intervention interview with the carer(s).
5. To investigate participant and carer's experience of the Social Story™.	Post-intervention semi-structured interview schedule (Appendix M) with the participant and carer who used the Social Story™ intervention.  Thematic Analysis and IPA conducted.

### **3.4 Procedure**

Following participant referral to the study, the researcher met with the potential participant to explain the study and seek consent. Once consent was obtained the participant and carer were involved in a setting up phase, which defined the situation which the story would target and the behaviours to be monitored. Functional analysis was undertaken to better understand the difficulties in the target situation and the Social Story™ was created. They then progressed through the baseline, intervention, fade and maintenance phases (as outlined in detail in Appendix N).

### **3.5 Data Analysis**

#### **3.5.1 Quantitative**

Behaviour recordings were inputted into Microsoft Excel and graphs were created to visually examine the change in behaviour over time. Researchers have recommended visual inspection of the data in single case studies (Kazdin, 1981; Parsonson & Baer, 1992). It has been suggested that visual inspection prevents over-sensitive interpretation of treatment effects and that clinically significant effects will be visually observable (Brossart *et al.*, 2006; Parsonson & Baer, 1992). Further statistical analysis was considered given the relatively recent developments in statistical analysis for single case design research. However several articles reviewing and comparing different single case design statistical analysis have shown that different statistical tests can yield varying results (Nourbakhsh & Ottenbacher, 1994; Parker *et al.*, 2005; Shadish, 2014). Existing methods of statistical analysis for single case design did not fit with the study design used (AB with fade and maintenance phases) and therefore no further statistical analysis was conducted.

#### **3.5.2 Qualitative Thematic Analysis**

Thematic analysis was conducted on the detailed interview notes, which were verified with audio recordings. There have been examples of research which has used thematic analysis from notes, as opposed to full transcripts (Clutterbuck *et al.*, 2009). Data was analysed by the researcher using thematic analysis as described by Braun and Clarke (2006). Thematic analysis was used to gain a rich description of carer and participant experiences. Themes were derived inductively and semantically on an explicit surface

level. The researcher took a stance that is described as 'critical realism' (Barnett-Page & Thomas, 2009).

### **3.5.3 Interpretative Phenomenological Analysis**

More in-depth analysis was undertaken using IPA to explore the experience of the participant and carer and the meaning they made of using a Social Story™. The audio-recorded interview was fully transcribed by the researcher, changing only names to protect confidentiality. IPA was undertaken following the six step method outlined in Smith *et al.*, (2009). The first four of six steps were followed; reading and re-reading text to become immersed in the data; initial exploratory noting of meaning and language line by line; developing emergent themes from these notes; searching for connections across emergent themes. Steps five and six concern cross case analysis, which was not relevant to this single case study. The initial deductive thematic analysis had highlighted surface themes that drew on the cognitive behavioural theories underpinning the Social Story™ to aid information processing and increase understanding thus reducing distress. This was to be expected as Social Stories™ have been advertised as an intervention that provides contextual information that those with ASD struggle to pick up on and make sense of. The IPA invited an explicitly interpretative analysis, and opened up possibilities for more psychodynamically informed concepts. Through discussions in supervision it was decided to focus on the more relational aspect that was coming through the data, drawing on theories such as attachment theory (Bowlby, 1969), and the use of object relations concepts such as boundaries and containment (Brown & Stobart, 2008; Winnicott, 1953; Winnicott, 1960). Emergent coding focused on these ideas and supervision was used to discuss and explore the emergent codes to ensure that these interpretations were supported by the data. Reflexivity processes were engaged in through personal reflection and the use of supervision, which questioned the robustness of the interpretations and ensured that interpretation bias was avoided. Through supervision discussions and analysis of the transcript it appeared that the emergent theme codes could be clustered together into super-ordinate themes that all seemed be linked to one significant over-arching theme. See Appendix S for a section of the transcript and the analysis initial comments on the data and ideas about emergent themes.

### **3.6 Ethics**

This research project was approved by the NRES Committee East Midlands and Local Research and Development (R&D) (see Appendix T for NRES correspondence).

## **4. RESULTS**

The section starts by explaining the target situation and psychological formulation that the Social Story™ was informed by to provide the reader with the context around the case study. The quantitative behavioural monitoring, measure of distress and thematic analysis will be summarised and the IPA findings will be covered in more depth.

### **4.1 Target Situation, Psychological Formulation and Creation of the Social Story™**

During the initial meeting, Sarah, Michelle and the researcher agreed that the target situation for the Social Story™ was while Michelle was making dinner. They explained that during this time Sarah often attempted to interact with her mother in the kitchen and did not seem to understand that her mother was busy at this time. When Sarah was asked to “wait a minute” she would continue talking. If Sarah was asked to leave the kitchen, she would stand in the doorway or the hallway just outside of the kitchen and continue talking. Michelle reported that there were often accidents in the kitchen as a result of Sarah being in the way and Michelle becoming distracted by Sarah talking to her, such as dropping food or burning herself. These interactions would often lead to shouting at each other as a result of both of their frustrations at the situation. The goal for the Social Story™ was to help Sarah understand when her mother was unable to talk to her.

Psychological formulation (informed by the functional analysis and conversations with Michelle and Sarah) indicated that Sarah sought her mother out due to feeling anxious and worried. The anxiety or worries were sometimes related to something that had happened during that day, or something that was due to happen later that day. Often they would have conversations and Michelle would offer reassurance or help Sarah to problem solve. However when Michelle was preparing dinner, she was unable to reassure Sarah as she was busy with her task of cooking. Michelle would often feel guilty for not reassuring Sarah at this time and so would stop cooking and find Sarah in



the living room to check she was okay. This reinforced Sarah's behaviour of interrupting her mother when she was cooking and led to confusion about when it was acceptable to interrupt her mother and when it was not. It was further formulated that the prompts Michelle gave her were not very clear and that Sarah interpreted things in a literal way due to her autism. For example, when Michelle asked her to leave the kitchen and Sarah went to stand in the doorway, Sarah was following her mother's instructions literally, when what Michelle meant was for Sarah to sit in another room and not continue to talk to her.

The Social Story™ focused on explaining to Sarah why her mother was not able to talk to her when she was preparing dinner and how Sarah would know when mum was not able to talk. It explained what her mother might say and what she meant by this. It also explained when Sarah was allowed in the kitchen (when she helping with preparing dinner) and what she could do while she waited for her mother to finish preparing dinner. The Social Story™ was tailored for Sarah's visual impairment by using large font and black line drawings which were easier for her to see. The Social Story™ can be found in Appendix U.

## 4.2 Behaviour Monitoring

A total of six behaviours were monitored throughout the phases of the study; four undesired behaviours and two appropriate behaviours. Table 2 shows the six behaviours and the mean frequency at which they occurred during each phase.

Table 2. Mean frequency of behaviours during each phase

	Baseline	Intervention	Fade	Maintenance
<b>Undesired Behaviours</b>				
Starting a conversation in the kitchen	3.00	0.53	0.55	0.70
Starting a conversation from the hall/living room	2.30	1.20	0.65	0.70
Watching in the doorway	0.70	0.06	0.25	0.40
Making requests	1.10	0.45	0.25	0.25
<b>Appropriate Behaviours</b>				
Not making conversation	0.00	0.00	0.05	0.05
Occupying herself	0.40	0.85	0.40	0.50

The total frequency of undesired and appropriate behaviours was depicted in a graph (Figure 1) so that changes could be visually examined. This graph shows that by the

third target situation in the intervention phase there is a noticeable decrease in undesired behaviours, suggesting that the story had to be read a number of times before Sarah was able to modify her behaviour. Towards the end of the fade phase and during the maintenance phase the undesired behaviours increased, although not to the same frequency as the baseline phase. During the first half of the maintenance phase the Social Story™ was read twice a week and in the final half of the phase it was read once a week. It appears that reading at this reduced frequency has led to some increase in the undesired behaviours. The Social Story™ appears to have led to the appropriate behaviours being displayed slightly more regularly, although not at an increased frequency within each target situation occurrence. Figure 1 was shared with the participant and carer at the end of study to demonstrate the change in Sarah's behaviour.

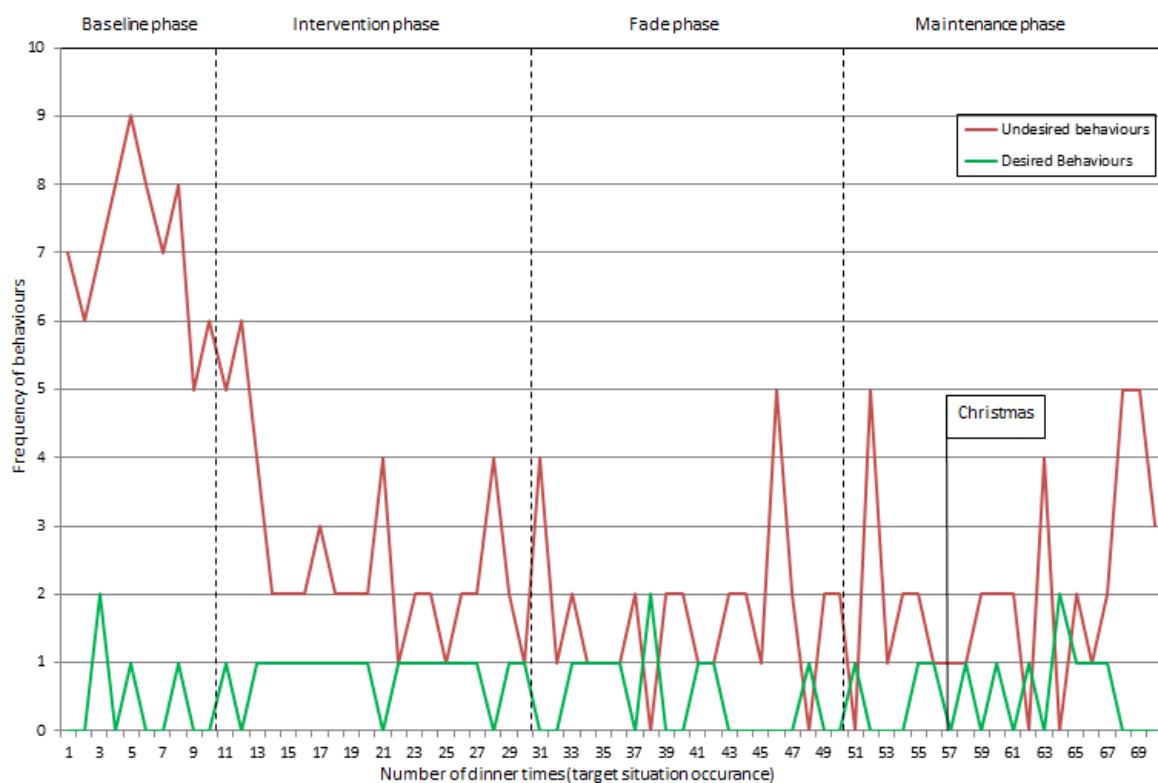


Figure 1. Frequency of the total undesired and appropriate behaviours over the phases of the study.

### 4.3 Patient Rated Outcome Measure (PROM)

Sarah completed the PROM at the initial meeting and again at the interview after completion of the phases of the study. She was asked “how happy or sad do you feel about following mum when she is cooking in the kitchen?” At the initial session she rated herself at point 2 (out of 12), indicating that she was very sad about this situation. At the end of the study she rated herself at point 11, indicating that she was very happy about managing when mum was cooking dinner. This suggested that the Social Story™ had helped to reduce the distress Sarah had felt around managing when her mother was cooking dinner.

### 4.4 Thematic Analysis

The thematic analysis separated Sarah’s and Michelle’s experience and created a thematic map for each of the participants. The analysis started with initial coding of the data to identify codes, which were organised into preliminary themes, and then further analysed to create final themes that were well supported by the data. Figures 2 and 3 present the thematic maps with the themes and sub-themes.



Figure 2. Thematic Map for Sarah’s interview

For Sarah the main theme was ‘knowing what to do’, which seemed to be really important to Sarah. She had a positive experience of using the story and her favourite part of the story was the last page which listed what she could do to occupy herself and had a picture of a person with their thumbs up. She also seemed to have a clearer understanding of when she could be in the kitchen to help mum. The sub-theme of ‘forgetting’ encapsulated Sarah’s difficulties remembering what to do at times. She

stated that she asked her mother to read her the story “because I keep forgetting sometimes”. The second sub-theme of ‘another story’ reflects Sarah’s ideas about what she could have a Social Story™ about next, for example “when transport don’t turn up”.

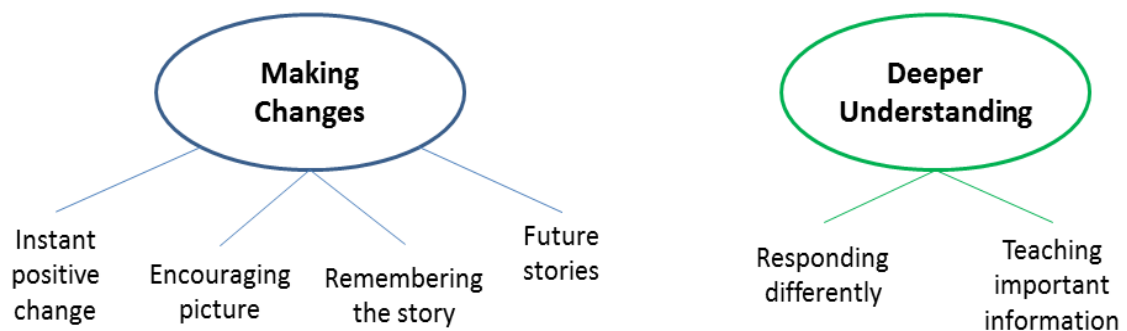


Figure 3. Thematic Map for Michelle’s Interview

For Michelle the theme of ‘Making Changes’ is used to describe the elements that were part of the way the Social Story™ helped to change Sarah’s behaviour, the observations Michelle had about the intervention’s impact and it’s applicability for the future. The sub-theme of ‘instant positive change’ encapsulated the enthusiastic way that Michelle talked about the Social Story™ which “worked instantly”. The sub-theme of ‘encouraging picture’ is about a particular picture in the Social Story™ which had a very positive impact. The picture is of a person with their thumbs up and Michelle observed that Sarah looked at this picture a lot and that it was “encouraging” and “quite a good prompt” to help Sarah “stick” to the story. This picture may work as a reward to Sarah, increasing the positive behaviours in line with operant conditioning theory. The sub-theme of ‘remembering the story’ includes the challenges for Sarah to remember new information, to maintain the positive changes and how Michelle and Sarah used the story. Michelle described how they built reading the story into their routine, and did it at the same time every day. Michelle talked about not being sure that Sarah would be able to take in the information in the story stating “I didn’t think she’d keep all that information but she’s obviously kept in key words and bits of information”. The final sub-theme of ‘future stories’ highlights the hope that Michelle

had for Social Stories™ to be used again; “I can think of lots of situations where we can use a story again”.

The second main theme ‘Deeper Understanding’ encapsulates Michelle’s increased understanding of Sarah’s difficulties as a result of the intervention and how this impacted on the way she interacted with Sarah. Michelle said her experience of using a Social Story™ had “opened my [her] eyes” and she talked about a new realisation of the “kind of difficulties she [Sarah] has processing things and retaining them”. The sub-theme ‘responding differently’ reveals Michelle’s change in the way she interacted with Sarah; “when they [her children] don’t do what I say then I think about what I’ve said” and “I’ve learnt to be clearer about what I say”. Michelle also talked about her behaviour having changed as a result of the Social Story™; “reading the story also helps remind me of what I should be saying”. The sub-theme ‘teaching new information’ reflects Michelle’s observation that the Social Story™ was “like teaching a new skill”. Michelle stated “I had thought it looked like quite a lot of information but as you read it you realise that every bit is really important in explaining to her why she can’t come into the kitchen”.

#### **4.5 Interpretative Phenomenological Analysis**

The Thematic Analysis highlighted the more explicit cognitive behavioural explanations of the Social Story’s™ benefit based on an information processing understanding, as the themes relate to communicating knowledge, increasing understanding and recall, and reinforcing the desired behaviours. In contrast, the IPA delved further into the material and illuminated a more relational aspect of using the story that came through the data. All the themes seemed to be linked to one over-arching theme; ‘need to contain separation anxiety’. Within this, the themes could be clustered under three super-ordinate themes; ‘story helps manage separation anxiety’, ‘strengthening the relationship between mother and daughter’, and ‘mother’s anxiety’. Table 3 shows the over-arching theme, super-ordinate themes and the themes within them.

Table 3. Table of IPA Themes

<b>Over-arching theme:</b> <b>Need to Contain Separation Anxiety</b>		
<b>Super-ordinate:</b> <b>Story Helps Manage</b> <b>Separation Anxiety</b>	<b>Super-ordinate:</b> <b>Strengthening the</b> <b>Relationship between</b> <b>Mother and Daughter</b>	<b>Super-ordinate:</b> <b>Mother's Anxiety</b>
Story acts as a transitional object	Reading the story is dedicated time together	Not responding to Sarah is stressful
Mentioning the story helps Sarah to tolerate separation	Praise and encouragement	Professional involvement offers containment for Michelle
Sarah knowing when she can help mum is containing	Change at the right pace	
Sarah uses the story to seek contact with mum	Acceptance and attunement	
Stories can help manage anxiety	Co-constructing meaning	

#### **4.5.1 Story helps manage separation anxiety**

This super-ordinate theme comprises five sub-themes; 'story acts as a transitional object', 'mentioning the story helps Sarah to tolerate separation', 'Sarah knowing when she can help mum is containing', 'Sarah uses the story to seek contact with mum' and 'stories can help manage anxiety'. These all were related to how the story helped Sarah to be able to contain and manage her anxiety at being apart from her mother Michelle when she was cooking in the kitchen. In addition, the structure of the Social Story™ process helped Michelle maintain boundaries in a consistent and reliable manner, and gave Sarah regular one-to-one time with her mother that may foster a more secure attachment relationship.

### *Story acts as a transitional object*

This theme encapsulates the relational interpretation that the story acted as a transitional object to help Sarah manage the absence of her mother from the room (while her mother was in the kitchen). Michelle talked about Sarah looking at the story and stated:

“I don’t know what kind of erm what she’s picking up out of that. She’s clearly picking something useful out of just holding it” (l. 300).

This suggests that it was not just the information within the story that was helpful, but that just holding the physical story was helpful to Sarah. Sarah stated:

“if I look at that I don’t need to go in” (l. 308).

Here Sarah is saying that if she looks at the story she doesn’t need to go into the kitchen to seek her mother out. As Sarah is unable to read the story herself, the physical story book seemed to have come to symbolise the secure feelings associated with that regular intimate reading time with her mother and this was in some way reassuring for Sarah and helped her to manage her need to be physically close to her mother. The psychological formulation of the target situation highlighted that Sarah seemed to enter the kitchen when she was anxious and wanted reassurance from her mother. It was wondered whether Sarah was able to independently manage this feeling of anxiety when her mother is not in the room, and perhaps the physical story book, which she had read with her mother earlier that day acted as a transitional object making it possible for her to tolerate the anxiety of being apart from her mother. This is further highlighted later in the interview when Michelle stated:

“I think it’s always going to need to .... be there even if it’s not read all the time or looked at it’s just having that there to have a glimpse at or to look at that picture you know it could be as simple as that” (l. 575).

This again suggests that the physical object of the story book is important as a transitional object, in the way that a teddy or comfort blanket can reassure an anxious child.

*Mentioning the story helps Sarah to tolerate separation*

This theme reflects the observation by Michelle that if Sarah came into the kitchen while she was cooking, mentioning the story helped Sarah to leave the kitchen.

Michelle stated:

“What would I say to you? Sarah remember the story yeah and then you’d remember straight away wouldn’t you” (l. 219).

This could be understood as Michelle prompting Sarah to help her cognitively remember, and having remembered that she had been asked to occupy herself she was then able to do this. However a more relational interpretation is that mentioning the story helped Sarah to recall the sense of emotional containment she had while she had looked at the story with her mother, which allowed her to feel secure enough to leave her mother in the kitchen. Michelle described the way this conversation between them happens:

“although she is coming in more it’s dealt with quite quickly. You know I’ll say Sarah remember the story and actually the bit I always use in it is remember mum’s trying to concentrate and that always that really stuck didn’t it in your mind and you’ll say now mum I know you’re trying to concentrate but can I and I’ll say well you know I’m trying to concentrate so we’ll talk after dinner so we’re kinda still remembering bits of the story without actually reading it and that seems to ermm work quite well doesn’t it Sarah” (l. 234).

Here it can be seen that Sarah approaches her mother in the kitchen and Michelle is able to ask Sarah to wait until after dinner, and do this in a way that supports Sarah to wait for interaction with her mother. Prior to the Social Story™ Sarah was not able to leave her mother when asked to wait until after dinner. However following the story it seems that Sarah is able to respond to Michelle’s prompts and Michelle comments that this is “dealt with quite quickly” and that Sarah would remember “straight away”. The theme ‘story acts as a transitional object’ suggests that the story acted as a transitional object to help Sarah tolerate time away from her mother and it seems that mentioning the story in some way taps into this containment and supports Sarah to



leave the kitchen. This could be happening in parallel to the more cognitive behavioural interpretations arising from the thematic analysis.

*Sarah knowing when she can help mum is containing*

This theme encapsulates the idea that Sarah found it helpful to have clear boundaries regarding when she could help her mother. When asked what she liked about the story she responded:

“when I can help mum” (l.11).

It is clear that Sarah likes to be with her mother and that helping her mother in the kitchen is enjoyable. The story explained when she could help her mother and what to do after helping her mother. Michelle also commented on this being helpful:

“there’s gonna be that bit where she can come in and help it might not be every night but it was very clear on when she can come and when mum said errm thank you Sarah for helping errmm if you stick to what it says in the story word for word really I think that works.” (l. 361).

Whilst this can be interpreted in terms of rewarding Sarah for staying out of the kitchen in operant conditioning terms, other interpretations are also possible. The importance of the clear boundaries around helping Michelle in the kitchen and how effective this is could be interpreted as providing emotional containment for Sarah by giving a consistent and reliable aspect to her mother’s interactions with her. It was also wondered whether the structure of the intervention was also containing in some way for Michelle, as she was able to be very clear with Sarah particularly when Sarah had finished helping. Michelle talks about saying “thank you Sarah” and sticking to “what it says in the story word for word” suggesting that she feels clearer about how to manage asking Sarah to leave the kitchen.

*Sarah uses the story to seek contact with mum*

This theme reflects that Sarah is often the one initiating the reading of the story. During the research process the frequency with which the story was read was gradually reduced from daily to every other day to twice a week. It seemed that Sarah was the one who knew when the story needed to be read. Michelle commented:

“Sarah would know that we didn’t have it yesterday and we were having it today so yeah she was on it should I say. There was no chance of forgetting” (l. 434).

This suggests that to Sarah reading the story with her mother was important and that she would not allow it to be forgotten, and it gave a context for proximity seeking behaviour, and pleasant, reliable interaction with her mother. At the time of the interview Sarah commented twice:

“occasionally I need it reading to me” (l. 23 and 32).

This shows how the story was still needed sometimes and that Sarah still sought out for it to be read to her. The use of the words “to me” could be interpreted as Sarah needing that contact with her mother. Michelle said to Sarah:

“You say can you just remind me and we’ll go through the story won’t we and read it. And we’ve said if you ever need it you just need to ask me and that’s what you do.” (l. 284).

This demonstrates the shared agreement between the two of them that requesting the story is an acceptable way to seek contact with mum and that mum will read the story when Sarah asks for it. This may be containing for Sarah as she knows that her mother will respond to her requests to look at the story together.

#### *Stories can help manage anxiety*

This theme reflects Sarah and Michelle’s idea for another Social Story™. Sarah suggested a story for when:

“transport don’t turn up” (l. 93).

Michelle explains why this time is challenging:

“I mean the transport Sarah got a bit anxious this morning because it was late but she gets equally anxious when it’s early” (l. 122).

Their suggestion that this is a time where a story would be helpful suggests that they consider Social Stories™ as something that can help to manage anxiety. Michelle describes this situation in a way that suggests that she also finds this a difficult time:

“some mornings when things are getting a little bit anxious and I’m trying to find out where your taxi is and you’re getting all hot and bothered and you decide you’re not going because the taxi is late.” (l. 127).

Here Michelle uses language which suggests that she is distancing herself emotionally from the situation as she talks about it. She uses the impersonal word “things” and the minimising language of “a little bit” which hints at how difficult it might be for her to talk about this situation. It is interesting that she uses the word “things” rather than saying Sarah is anxious, this might suggest that Michelle is also feeling anxious at this time. Michelle goes on to use a stronger phrase of “hot and bothered” hinting at how challenging this situation really is for them. Later in the interview Michelle states:

“it would be a very useful one because you do get very worried when transport is late or when they’re early. Maybe different ways you could deal with things yeah.... To help you so you don’t get so worried yeah?” (l. 461).

This further highlighted that Michelle thought a Social Story™ could help in this situation where Sarah is waiting for her transport to arrive. It is interesting to note that this is a time of separation for Sarah and Michelle, Sarah is waiting for her transport to take her to her daily activities and thus leaving her mother. The anxiety does not seem linked to the transport being early or late, and she is anxious either way, so perhaps the anxiety relates to separation from her mother. This links into the over-arching theme of ‘need to contain separation anxiety’, which it seems that the present story helped to do and that they hope that the next story will also help to do.

#### **4.5.2 Strengthening the relationship between mother and daughter**

This super-ordinate theme reflects the relational changes between mother and daughter that seem to have come about in the process of sharing the story and the ways in which they made sense of their experience in the interview. It contains five sub-themes; ‘reading the story is dedicated time together’, ‘praise and encouragement’, ‘change at the right pace’, ‘acceptance and attunement’ and ‘co-constructing meaning’.

### Reading the story is dedicated time together

This theme reflects the time Michelle and Sarah set aside to read the story together.

Michelle commented:

“generally it was just me and Sarah before M [brother] came home which seemed to work quite nicely” (l. 320).

The pair chose a time to read the story when it would be just the two of them, which Michelle felt worked well. Michelle and Sarah go on to say:

Michelle: “I think Sarah wanted to keep it between me and her because it was between me and Sarah so that was quite nice wasn’t it us reading?”

Sarah: yeah” (l. 323).

This suggested how important both of them felt it was to have this one to one time together and that this was an enjoyable experience for them. It could be further interpreted that this daily time together acted to strengthen the security within the parent-child bond. This analysis suggests that the story book acted as a transitional object which helped Sarah tolerate the separation from her mother. This dedicated one-to-one time to read the story is likely to have supported this process, by allowing them to have some time where they closely bond around the story. For Sarah this feeling of a secure bond may have become symbolised in the physical story book, which then comes to act as a transitional object.

### Praise and encouragement

Throughout the interview there were numerous occasions where Michelle praised Sarah for her improved ability to stay out of the kitchen while she was cooking:

“That’s great Sarah that’s really good. Look that’s really worked” (l. 167)

It seemed really important to Michelle to offer lots of praise to Sarah for her achievement, this positive interaction is likely to be beneficial in their relationship and could play a role in strengthening it. There are also examples of Michelle encouraging Sarah to continue with these positive changes:

“it would be good if you kept to it yeah” (l. 56).

Michelle is encouraging Sarah to continue tolerating being apart from her when she is cooking. Michelle talks about praising Sarah when she had helped in the kitchen and then had to leave:

“then when obviously she’s finished thank you for your help I really appreciate that and kind of bigging up everything that she’s helped you with” (l. 368).

Michelle’s use of the term “bigging up” indicated her intent to really praise Sarah even when it seems like something small. It could be interpreted that this praise and encouragement from Michelle supported Sarah to internalise this positive achievement and begin to unconsciously think of herself as someone who can tolerate separation. This positive interaction between them and the internalisation of this positive achievement may act to strengthen the bond between them.

#### *Change at the right pace*

During the interview Michelle talked about the flexible nature of using the Social Story™ and that reading the story was gradually reduced:

“I think it was quite flexible in or quite flexible to a point in kind of gradually reducing the reading of it rather than errm doing it too quickly. I think some people might cope well with it being reduced quicker but I think for Sarah it needed to be a slow sort of withdrawal and to still have it there at hand you know” (l. 572).

Michelle talked about how a slow withdrawal of the story was better for Sarah, acknowledging that this may be different to other people. Michelle goes on to say:

“Having that flexibility about how slowly we do it or how quick was good because if that had been too quick we might not have got the same sort of results” (l. 579).

Michelle felt that going at their own pace was an important part of the success of the story. The use of the word “we” suggests that the pace of withdrawal was also important for Michelle, perhaps supporting her to gradually withdraw from interacting with Sarah while she was in the kitchen. The pace at which they were reading the story was important, as the story seemed to act as a transitional object for Sarah to tolerate being apart from her mother. It seemed to support both Michelle and Sarah to move towards feeling more comfortable being apart while M was in the kitchen

Having change at the right pace is also emphasised when Michelle talks about having more social stories:

“So we’ll do it slowly like we did with this one yeah?” (l.475).

This further suggests that it is important for change to be at a manageable pace for both of them.

### Acceptance and attunement

This theme reflects Michelle’s deeper understanding of her daughter Sarah, which seems to have helped her to be more accepting of Sarah’s differences and more attuned with her needs. Michelle stated:

“I realised that actually they haven’t understood what I’ve said and it’s not because they’re not listening to what I’ve said they are actually really struggling with what I’m asking them to do” (l. 500).

Here Michelle is talking about both Sarah and her son (who also has ASD), and this sentence suggests that Michelle might have thought that her children were not listening to her instructions deliberately, but now she sees that they are struggling to understand her. The use of the words “actually really struggling” highlights that this is quite a change in perspective for Michelle and reflects that through a different perspective of her children’s difficulties she has become more attuned to them. Michelle talks about how she has changed the way she communicates with her children as a result:

“it’s definitely helped to make me stop and think what I say” (l. 518).

Michelle reflects on the extent to which using a Social Story™ has helped her:

“I’ve definitely got more out of it than you know I or what it was even set up for. It wasn’t set up for me to come away understanding my children better” (l. 525).

This statement reflects Michelle’s surprise at what she has learnt from using a social story and that this new understanding applies to both her children. The idea that she “got more out of it” than what “it was even set up for”, hints at the relational benefits of using the story and how this links to her different understanding. This

understanding seems to help Michelle be more attuned to her children and to interact differently to meet their needs.

### Co-constructing meaning

This theme reflects that Michelle and Sarah seemed to be making sense of their experience together; Michelle supporting Sarah to understand their experience and Sarah sharing her thoughts, which Michelle supported. Sarah and Michelle chose to remain together for the interview and although questions were directed at each of them as individuals, there were times that they spoke together about their experience. There were times that Sarah repeated Michelle, for example when talking about the pictures in the story:

Michelle: “maybe that had a bit too much in it for her, didn’t it?”

Sarah: “that one had a bit too much in it” (l. 74).

This repetition suggested that Sarah was using her mother’s expressions to help her make sense of the experience. There were times when Sarah wasn’t sure she was making sense:

Sarah: “does that make sense?”

Michelle: “perfect Sarah... you are saying it perfectly” (l.29).

Here Michelle is validating Sarah’s sense making and thus supporting and encouraging her to express herself. Michelle also comments on things that Sarah has mentioned:

“good point actually Sarah because that was actually a really good point to say because I would have forgot to say that and that was one of your favourite bits wasn’t it” (l. 61).

Michelle is again validating Sarah’s sense making and noticing for herself how important this piece of the story was and so incorporating this into how she has made sense of the experience. The co-constructed meaning of their shared experience may act to strengthen their relationship by having a more shared sense of what it meant to use a Social Story™ together.

#### **4.5.3 Mother's anxiety**

This super-ordinate theme encapsulates themes that reflect Michelle's feelings about using a Social Story™ with two themes; 'not responding to Sarah is stressful' and 'professional involvement offers containment for Michelle'. The two super-ordinate themes already described focused on the ways the story supported Sarah (story helps manage separation anxiety) and Sarah and Michelle's relationship (strengthening the relationship between mother and daughter). This final theme highlights the challenges faced by Michelle in the process of separating from Sarah when in the kitchen.

#### **Not responding to Sarah is stressful**

Michelle talked about how she found the process of encouraging Sarah to stay in the living room while she was in the kitchen difficult. Michelle stated:

Michelle: "But the thing I've got not to do is that I'll sometimes feel a bit guilty

Interviewer: "okay"

Michelle: "that I've sent her away" (l. 248).

Here Michelle is acknowledging that she feels guilt for sending Sarah out of the kitchen. She goes on to say:

"normally it can wait can't it until I've finished dinner" (l. 255).

Here it seems Michelle is trying to justify to herself that it is okay to wait to interact with Sarah. She seems to be asking "can't it" to Sarah, perhaps seeking reassurance from Sarah that she can wait. This hints at how difficult emotionally this might be for Michelle. Michelle also stated:

"I I really have got to not be kind of pulled into this conversation that will make us end up back to where..." (l. 268).

Michelle use of the words "pulled into" suggests the strong urge she feels to engage with Sarah and the repeated use of "I" at the start of her statement suggests that it is an effort for her not to be "pulled into" conversation. Michelle is reluctant to finish the sentence, letting it trail off. This can be interpreted that it is too difficult to think about how things were before they were able to tolerate time apart from each other when



Michelle is cooking. It seems that the adjustment to being able to spend time apart is a difficult one, not just for Sarah but for Michelle too. Michelle comments that she has learnt ways to manage this:

“so I’ve learnt that I that I’ll just maybe turn the music up a little bit louder just so she can still talk to herself about it and I’m not inclined to you know sort of get involved in in a conversation that can wait and I remember that erm” (l. 272).

Here Michelle is talking about turning the music up so she cannot hear Sarah and therefore is less inclined to interact with Sarah. This statement hints at how this does not yet feel comfortable for Michelle, at the start she stated “that I that I’ll” repeating herself suggesting that it is hard to get these words out and perhaps difficult to connect with the feelings this brings.

#### *Professional involvement offers containment for Michelle*

This theme reflects that the input of professionals supports Michelle and perhaps provides some containment for her. Michelle comments:

“I think because somebody else I know I’ve said before but someone has set that for Sarah..... you did that for Sarah... erm... yeah it’s not something I’m telling Sarah this is something that someone else is saying is a really good idea and this is going to help us erm... so she took that on board. If I had written the social story I don’t think it would have had the desired sort of effect really.” (l. 380).

Michelle believed that because the story was developed by someone else (a professional) that this helped Sarah to listen it. Michelle seems to doubt her own effectiveness in her relationship with Sarah and she stated that Sarah might not have listened as well if she had created the story.

During the interview at several points Tracey (the Community Psychiatric Nurse) is mentioned. It seems that Michelle is keen for the interviewer (Nicol) to liaise with Tracey to support them to continue using social stories:

“So that’s what erm Nicol’s going to speak to Tracey about to see if we can do some more social stories erm for other things” (l. 464).

It was wondered whether professional involvement is in some way containing for Michelle, who it seems find it hard to manage and contain her and Sarah's separation anxiety.

#### **4.5.4 Need to Contain Separation Anxiety**

This is the over-arching theme which all super-ordinate themes seem to fit with.

Michelle and Sarah chose to have a Social Story™ to support them when Michelle was cooking dinner and Sarah was required to sit in another room. This is a time when they needed to be able to be apart, however Sarah was often very anxious and sought out her mother in the kitchen. It seems that this anxiety may be related to the separation from her mother, which was challenging to manage. The super-ordinate theme 'story helps manage separation anxiety' encapsulates all the ways in which the story supported Sarah to tolerate being apart from her mother and helped her to feel emotionally contained. The super-ordinate theme 'strengthening the relationship between mother and daughter' incorporates the processes around using the story which supported Michelle and Sarah to have a stronger bond which could withstand the period of separation while Michelle was in the kitchen. This strengthened relationship was able to be more emotionally containing for Sarah, further supporting her to tolerate separation. The final super-ordinate theme 'mother's anxiety' highlighted that this was a challenging process for Michelle, as well as Sarah, and that professional input provided containment for Michelle.

## **5. DISCUSSION**

### **5.1 Discussion of Results**

This research paper asked "What are the experiences of an adult diagnosed with a Learning Disability and Autism Spectrum Disorder, and their carer who have used a Social Story™?" It aimed to explore the lived experience of using a Social Story™. The project had initially intended to use Thematic Analysis to explore themes relating to experience of using a Social Story™ across several cases. However only one participant and carer pair completed the study and therefore IPA was conducted in addition as an idiographic method suitable for analysing one case. Quantitative data demonstrated that the undesired target behaviours reduced following the introduction of the Social

Story™. A Patient Rated Outcome Measure (PROM) was used as a measure of distress and this showed that the participant's distress related to the target situation was reduced following the Social Story™. The qualitative data was initially analysed using Thematic Analysis (Braun & Clarke, 2006) and subsequently fully transcribed and analysed using IPA (Smith *et al.* 2009). The Thematic Analysis highlighted the more explicit cognitive behavioural explanations of the Social Story's™ benefit based on the information processing understanding that Social Stories™ are derived from. This is the idea that Social Stories™ provide social information that the individual is unable to attend to and process by themselves (Ali & Frederickson, 2006; Gray & Garand, 1993; Gray 2010). Sarah's experience was reflected in one main theme; 'knowing what to do'. Michelle's experience was organised into two themes; 'making changes' and 'deeper understanding'. The IPA focused on the more relational themes that were coming through the data, drawing on attachment theory and psychodynamic ideas around object relations, boundaries and emotional containment. One over-arching theme 'need to contain separation anxiety' encapsulated three super-ordinate themes; 'story helps manage separation anxiety', 'strengthening the relationship between mother and daughter', and 'mother's anxiety'. The findings from the Thematic Analysis are not surprising as Gray (2010) advocated that Social Stories™ aim to provide information to support the individual's understanding of a situation and are also about supporting carers to change their behaviour too. The findings from the IPA offer something new and previously unexamined and therefore will be the focus of the discussion section.

The IPA suggested that the Social Story™ acted as a transitional object which offered emotional containment for Sarah and thus supported her to tolerate the separation from her mother while she cooked dinner in the kitchen. This was reflected in the theme 'story acts as a transitional object', which was within the super-ordinate theme of 'story helps to manage separation anxiety' and there are parts of this psychological process that are reflected in other themes. The theme 'reading the story is dedicated time together' highlighted the special one-to-one time that mother and daughter spend reading the story, which seemed to be a positive experience for them. It was interpreted that this reliable and structured time together with her primary

attachment figure provided a sense of security for Sarah, which became symbolised in the physical story book, allowing it to become a transitional object. It also seemed that talking about the story was containing, as reflected in the theme 'mentioning the story helps Sarah to tolerate separation'. The way in which the story was used seemed to provide some containing relational boundaries for Sarah, which were reflected in the themes of 'Sarah uses the story to seek contact with mum', 'Sarah knowing when she can help mum is containing' and 'change at the right pace'. These containing relational boundaries were part of the super-ordinate theme 'strengthening the relationship between mother and daughter'. It seemed as though their relationship was strengthened by Michelle's deeper understanding, which led to 'acceptance and attunement' and her 'praise and encouragement' of Sarah. The process of using the story at the right pace for them and making sense of their experience together also seemed to support a strengthening of their relationship, as reflected in the themes 'change at the right pace' and 'co-constructing meaning'. The super-ordinate theme of 'mother's anxiety' highlighted Michelle's challenges in trying to spend time apart from her daughter and the important role professionals might have played in containing her anxiety.

The findings from the IPA should be treated tentatively, as there are limitations in particular relating to the post-hoc decision to use this method of analysis which will be discussed more in-depth later in the discussion of the limitations of the study. Taking the Thematic Analysis and IPA findings together could suggest that the Social Story™ was helpful in both a cognitive information processing way and in a relational way, with these aspects running in parallel.

## **5.2 Social Story™ Application with Adults**

Social Stories™ were originally created for children with ASD and then later used by clinicians with adolescents and adults with varying Learning and Developmental Disorders and ASD. Existing research suggested ways in which the use of Social Stories™ with adults may differ from children, such as the length of time it may take adults to learn new information, tailoring Social Stories™ to make them age appropriate and assessing and understanding the target behaviour (Cihak *et al.*, 2012; Samuels & Stansfield, 2012). Although the present paper cannot offer any more

conclusions about whether Social Stories™ are an effective intervention for adults with ASD, this paper offers some thoughts on the psychological process that might be occurring when using a Social Story™ with an attachment pair and what this might mean for using this intervention with adults.

### **5.2.1 Implications of the relational understanding of using a Social Story™**

This paper suggests that there may be an important relational process taking place when sharing a Social Story™ about being apart from a parental care-giver. The IPA suggested that the story can help to manage separation anxiety and strengthen the relationship between the recipient and care-giver. For adults with Learning Disabilities it is suggested that they do not follow the “typical” development into an autonomous and independent adult due to their ongoing needs for support (Penketh *et al.*, 2014). Parents are often balancing encouraging independence and engagement with the activities peers of the same age are undertaking, with support and protection for their vulnerable adolescent or adult child (McConkey & Smyth, 2003). Social Stories™ may be particularly helpful in a parent-child dyad where the boundaries need to be clear, the child needs to be supported to use a symbolic level object containment and the parent needs to learn to tolerate the separation as well. Sullivan *et al.*, (2015) conducted an IPA study with adults with Learning Disabilities to explore their experiences of close relationships. One of the super-ordinate themes was ‘relationships feeling safe’. This encapsulated a number of things that the participants expressed about positive relationships, including reliability, consistency and trust. It was noted that these components map onto the ideas about secure attachments (Sullivan *et al.*, 2015). This suggests that using a Social Story™ may also be helpful in strengthening relationships in other close relationships, not just a parent-child relationship.

For adults whose primary care-givers are paid staff, the relationship between the adult service user and staff is potentially different. There is little research into the attachment style of adults with Learning Disabilities, although research suggests that adults with Learning Disabilities direct their attachment needs towards care-staff (Penketh *et al.*, 2014). Pockney’s (2006) exploration into the social networks of adults with a Learning Disability and their paid carers found disparity between how each of

them viewed their relationship. Adult service users viewed staff as friends, whereas the staff seldom saw their relationships with the service user this way and felt that they had little training in how to manage this relationship (Pockney, 2006). Research suggests that adults with Learning Disabilities can experience feelings of powerless and lack of agency in their close relationships (Sullivan *et al.*, 2015). It could be argued that this is especially likely in relationships with paid carers. Therefore it seems important for clinicians to carefully consider the adult with a Learning Disability's relationship with the carers in each instance of providing a Social Story™. This relational understanding could help clinicians think about what impact the Social Story™ and the way it is delivered might have on the recipient's relationships. In the present case study the recipient seemed to take on the role of asking for the story to be read and remembering when it should be read, this may help the story recipient feel in control, rather than reading the story being something that is forced upon them.

It is interesting to note that a further two participants and carers were recruited but neither completed the study. In both cases the carers were paid staff rather than family members, and both reported challenges with completing the behavioural recordings. Additionally in the case where the Social Story™ was given, the carers could not make the time to read this story to the individual. One tentative hypothesis about why carers could not make time to read the story might be that engaging in this close process of emotional containment felt too uncomfortable for them. Research has suggested that paid staff find it hard to manage the relationship with the adult they are caring for (Pockney, 2006). This is a very tentative idea, one that certainly requires more research to explore it, but could be a potentially valuable idea in helping to understand why carers can struggle to implement interventions.

### **5.2.2 Ways in which Social Story™ implementation may need to be adapted for adults**

It has already been suggested that adults may take longer to learn new information and therefore a Social Story™ may need to be read for longer period of time (Samuels & Stansfield, 2012). This paper highlighted the importance of going at a pace that fits with the recipient and carer, with the theme 'change at the right pace'. If there is a relational aspect to using Social Stories™ then it seems important to make decisions

with the recipient and carer regarding the frequency of reading the story and how it might be reduced. Alongside this relational aspect, it is also suggested that individuals with ASD have preferences for routine and predictability (Wing & Gould, 1979). As one of the aims of a Social Story™ is to reduce distress, it is important for it to be implemented in a way that is compatible with the participant's preference for routine and taking into account any potential relational needs.

The IPA theme of 'professional involvement offers containment for Michelle' highlighted that for the carer having professionals involved, and having the structure of a defined intervention can be reassuring and help them feel contained. This may of course be different for different carers, but is an important factor for clinicians to consider as how contained the carer feels could influence how well they can contain the person they are caring for. This is in line with Winnicott's image of a holding environment supporting mother's ability to hold and provide containment of the infant (Winnicott, 1960). Clinicians may want to think carefully about how they follow up their Social Story™ and provide support for the carer to continue using it. Gray (2010) notes how important reviewing Social Stories™ is and it seems that reviewing the story may also offer containment for the care-giver. This is an especially important point given that clinicians working in the NHS are working in the context of national and local budget cuts, cost improvement plans and service re-configurations. The role of the clinician in providing the Social Story™, monitoring it, and offering containment for the care-giver are all important aspects in ensuring the success of the Social Story™.

### **5.3 Limitations of the present paper**

IPA can be thought of as a whole methodology, informing the research design and data collection, as well as being a method of analysis (Smith *et al.*, 2009). As mentioned earlier in the paper, this project did not originally intend to conduct IPA and therefore there are limitations in the way the data was collected. The first limitation is that the semi-structured interview template was designed to explore the participant and carer's experience of using a Social Story™, to determine whether the participant's distress decreased and whether the client's behaviour change was maintained. Therefore the questions asked were guided by these aims. If the interview schedule had been developed with the intention to use IPA to explore the participant and

carer's experience of using a Social Story™ and the meaning they made of it, the questions asked are likely to have been different. For example, a question for the carer might have been "tell me about using the Social Story™" and then there may be greater flexibility to ask further questions related to the carer's response. Secondly, the interviewer's approach to interviewing would have been different with the intention to conduct IPA, for example taking a far more open exploratory approach and trying to elicit further responses to explore the meaning made by the participant/carers.

This research was undertaken with adults who had a diagnosis of a Learning Disability and ASD. Individuals with these diagnoses often have difficulties with verbal comprehension, verbal reasoning and expression which can make it challenging to undertake qualitative research with them (Beail & Williams, 2014). Challenges may include asking questions that the participant can understand (ensuring questions are not too long or linguistically complex), being able to gather rich data on the participants' experiences and ensuring that the participant does not acquiesce (Beail & Williams, 2014; Stigstad, 2014). There are only small numbers of published qualitative studies with this population, although this has increased in recent years, along with an awareness of the potential challenges of undertaking qualitative research with this population and suggestions about how people with Learning Disabilities could be supported to engage with this sort of research (Beail & Williams, 2014; Stigstad, 2014). In the present research the semi-structured interview was undertaken with both the participant and carer, as this was their choice. It seemed that this was helpful to Sarah and that Michelle was able to encourage her to voice her opinions and on one occasion acted as an interpreter when the researcher misunderstood what Sarah had said. In addition the theme of 'co-constructing meaning' suggests that it was important for them to make sense of their experience together. Despite this there is limited rich data directly from Sarah and it could be argued that the data was influenced by Michelle and therefore we cannot be sure that this is really a reflection of her experience.

This paper examines only one participant and their carer's experience, which some readers may consider a limitation as their experience cannot be generalised across other recipients of Social Stories™. The aim of the paper was to explore the experience



of an adult diagnosed with a Learning Disability and Autism Spectrum Disorder, and their carer who have used a Social Story™. Therefore this paper was concerned only with the subjective experience of this case study and analysis was conducted using a method that focuses on the in-depth exploration of an individual's experience (Smith *et al.*, 2009). No published research was found regarding a recipient's experience of using a Social Story™ (child or adult) and therefore this case study is important in forming the basis of research into this interesting area (Beail & Williams, 2014).

#### **5.4 Recommendations for further research**

There continues to be limited evidence base for the use of Social Stories™ with adults with ASD, Learning and Developmental Disabilities and therefore further research is needed to establish effectiveness. The present research suggests considerations for on-going research into Social Story™ effectiveness and also further research into the participant and carer's experience of using them.

Further research is needed to establish the effectiveness of Social Stories™ with adults and it seems that adults may benefit from adaptations in the way the intervention is implemented. Researchers might consider longer intervention phases and the gradual reduction of reading the story, and making decisions regarding this with the participant and their carer. It seems this individual tailoring of implementing the intervention supports success, both in providing the recipient longer to cognitively learn the story, but possibly also on an emotional and relational level. In addition working in collaboration with the participant is important to ensure that they do not feel powerless in the relationship. Furthermore, Gray (2010) suggests that the primary aim of using a Social Story™ is to reduce participant distress. Few studies into effectiveness explore the participant's distress and therefore further research should aim to undertake this.

Previous research has recommended functional analysis prior to creating the Social Story™ (Cihak *et al.*, 2012; Gray, 2010). This research project has highlighted the need for a more comprehensive systemic assessment, which also takes into account relational aspects. Two participants did not complete the study and it was wondered whether factors relating to the carer's beliefs about the origins of the behaviour, their

thoughts about change, their attitudes about Social Stories™ and their resources to implement the intervention were important. In order for staff to follow the behaviour recording and intervention they need to be fully invested in the process (McBrien & Candy, 1998). Allen (1999) highlights carers are unlikely to be able to implement an intervention from verbal instructions. Therefore it may be beneficial for there to be a greater emphasis on telling carers more about the ethos of Social Stories™ and modelling to them how to read them with the participant.

This paper highlighted the importance of the relationship between the carer and participant. It would be beneficial for further qualitative research into the carer and participant's experience of using a Social Story™ to be conducted; it is likely that this will illuminate other factors and psychological processes that may be involved in using a Social Story™. In addition it would be interesting to further explore whether there are differences between familial and paid carer's experiences using Social Stories™.

## **5.5 Conclusion**

This research offers interesting insights into complex psychological processes that may be occurring when using a Social Story™. The Thematic Analysis supports the anticipated use of the story to impart knowledge and increase understanding, and the reading and re-reading can aid recall. In addition the structure facilitated learning with positive reinforcement. The IPA of the participant and carer's experience of using a story suggested that for them it was related to a 'need to contain separation anxiety'. The story helped to manage the participant's anxiety through attachment and object relations processes (as reflected in 'story helps manage separation anxiety'), strengthened their relationship ('strengthening the relationship between mother and daughter') and helped to manage the carer's anxiety ('mother's anxiety'). It is possible that this process is occurring alongside the participant cognitively learning the story and responding to the behavioural instructions in the story. These findings are tentative, but interesting and warrant further research.

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# Critical Appraisal

During my first year of training when we began to choose an area to research, I can recall thinking that it was really important for me to pick something that would maintain my interest and enthusiasm for the whole process. The two and half years from picking a topic to completing the thesis seemed like such a long time. Now, as I come closer to the end point, I feel as though I achieved that goal. I chose the area of Learning Disabilities and Autism Spectrum Disorders (ASD) to focus on. I was drawn to this area as my cousin has autism. He is still a child and I do not feel I know him or his family particularly well. Having only worked with a few people with ASD at the time of choosing the project, it was not an area I felt I had a great deal of experience in. However, it was, and still is an area I am very interested in due to my family link with this disability. In this critical appraisal, I reflect on undertaking a meta-ethnography, the process of conducting research and my hopes for continuing research.

## **1. LITERATURE REVIEW**

The experiences of the families of those with Autism Spectrum Disorders (ASD) was the area I investigated for my literature review. I chose to do a meta-ethnography as it felt to me that a straight forward literature review was not considered advanced enough for a doctoral thesis. I first heard about meta-synthesis during a teaching seminar and my initial thought was “this looks beyond my level of understanding”. However I felt determined to find out more and work out how to undertake a meta-synthesis. Through lots of reading, I discovered that meta-synthesis was an umbrella term for a qualitative analysis of qualitative research and that there were in fact several different types. Comparing the different types it seemed that Noblit and Hare’s (1988) meta-ethnography was most appropriate.

The process of conducting the analysis was far more time-consuming than a standard narrative literature review. I developed a data extraction form; this is what had been recommended in our teaching seminar. At first it felt like I was doing this as a paperwork exercise, rather than something that would be helpful. However once I started filling this in, I realised that it was in fact going to be very helpful as it enabled me to have a one page summary for each article with all the key themes and metaphors. I found that using the data extraction form helped me to know the data

better through the process of pulling out the key themes and writing them down. The synthesis itself was a messy process involving lots of felt-tips pens, post-its and a lot of floor space! This was a process that I dreaded before starting but ended up getting really immersed in it, so much so that hours easily passed by without my realisation.

My meta-ethnography gave me a more in-depth understanding of what the families of those with ASD face. I wondered when I met my participant Sarah and her mother Michelle, what it was like for Michelle. I wondered whether any of the themes I had found would resonate with her experiences. I knew that Sarah had a brother with ASD, who I did not meet and I wondered how Michelle managed with two children with ASD. I recently saw my cousin and his family at a large family party. I wondered whether the themes I had synthesised would fit with their experience or whether they had a completely different experience. I wondered if they ever felt isolated from their family or friends and to what extent their lives revolved around autism.

## **2. UNDERTAKING THE RESEARCH PROJECT: CHALLENGES AND LEARNING EXPERIENCES**

This section of the critical appraisal shares the challenges of undertaking this research, reflections on the evolving nature of the project, my experience of qualitative analysis and what I have learnt from this process.

### **2.1 Undertaking the research project**

There were many challenges of undertaking this project; these included applying for ethics, recruiting participants, the practicalities of undertaking the project, interviewing a participant with a Learning Disability and ASD, and changes in supervisors. I am sure that these challenges are things that many researchers face, perhaps for me my research inexperience made these things greater challenges.

This was my first experience of applying for ethical approval through the NHS (having previously only applied for University ethical approval) and I found this a daunting prospect. It felt like a maze of organisations to navigate initially and guidance from the trust Research and Development Team (R&D) was invaluable. Starting with a detailed research proposal helped me to begin the application for ethical and local R&D

approval. This whole process really helped me to think about the smaller details of the project and how each part would be carried out. Designing a specially adapted information and consent form for people with Learning Disabilities was a longer process than anticipated, but I now consider this time well spent. Co-working with Speech and Language Therapists and a group of service users, really helped me to think about how potential participants might understand the project and what would be the best way to communicate this. This was a really valuable experience and I think this helped each of my participants to understand what I was inviting them to be involved in. The Ethics panel was a new experience and I was glad to have my field supervisor there for support. The process of designing my research taught me that putting in lots of groundwork at the start was hugely helpful in applying for ethical approval. I also learnt that the process of applying for ethical approval is in some ways an evolving process and that it is likely that the panel will ask for some minor amendments before granting approval. To do this process again for further research now seems less daunting and I now know that the R&D department are an excellent resource for those unfamiliar with the process of setting up a study and seeking approval.

I had expected recruitment to be straightforward and quick. I had expected this as I had conducted a scoping exercise prior to applying for ethical approval, in which the inclusion and exclusion criteria were shared with the MDTs to see if they would have suitable clients. This was done to check that the referral criteria were appropriate and not too strict. So having received positive feedback from staff that they would have lots of suitable clients, I was hopeful that I would have my target of four completed cases by Christmas 2014. Unfortunately this was not the case! On reflection there may have been a number of reasons why recruitment was a challenge. Perhaps the criteria for a simple, frequently occurring behavioural problem was too restrictive. It may have been that criteria such as low HONOS LD scores were not likely for people working in a secondary care service and suitable clients would not have usually have been referred or have met the criteria for secondary care services. As I was not undertaking a placement with the teams I was trying to encourage to refer participants to the study, maybe I felt 'faceless' to the staff and this made it difficult for them to liaise with me.

An alternative explanation might be that staff found it hard to remember the project and to refer appropriate clients. It had seemed to me that the research project was offering to undertake an intervention with clients and I had thought that staff would welcome the opportunity for someone to be taken off their caseload. However I wonder whether staff were unable to bear in mind the research project, given the pressured climate of the NHS, the volume of work they were undertaking and the way in which resources are stretched so thin. In an attempt to understand why referral to the project might be challenging for staff I used Menzies Lyth's (1959) psychodynamic theory of social systems as a defence against anxiety. It suggests that professionals have a number of ways in which they collectively defend themselves against the unconscious anxiety they experience. Menzies Lyth talks about nurses needing to resolve conflict about accepting the responsibilities that their role entails. She states that they might do this through a social redistribution of responsibility, viewing those junior to them as less responsible and those senior to them as more responsible. This was a way to project aspects of the self into others (Menzies Lyth, 1959). In the case of the present research perhaps the staff I was hoping would refer to the project were projecting their sense of responsibility into myself as the researcher. This may have resulted in them absolving themselves of their responsibility to refer and viewing it as the researcher's responsibility to find their own participants. It is not clear whether the staff would have thought the researcher to be senior to them, but perhaps as a different professional with a different function, which was not their responsibility.

The cases that did not complete the study were a challenge to work with from the start. There were difficulties communicating with the staff at both the day centre and care home, which with hindsight was indicative of the difficulties that followed. Both sets of staff required a lot of chasing and weekly phone calls. Undertaking this alongside my placements felt like a challenge which required me to hold these cases in mind at all times. I wondered if the staff felt as though they were providing a service to me by consenting to be involved in the research process and perhaps this made it feel as though I should be chasing them, rather than them returning my calls or following the instructions I had given them. I reflected on whether I had inadvertently given the staff this impression. Given the challenges that I was experiencing recruiting

participants, it is possible that staff picked up on my sense of relief when the participant and staff consented to be involved.

A further challenge of the project was interviewing a participant with a Learning Disability and ASD. Sarah was willing to engage in the interview; however she seemed to find it difficult to express herself and to share her thoughts on using a Social Story™. Sarah and Michelle chose to be interviewed together as this felt more comfortable to them. At times Michelle appeared to be acting almost like an interpreter for Sarah, on one occasion correcting me as the interview when I misunderstood what Sarah was pointing at. As I read the transcript during the IPA, I noticed that during the interview I had repeatedly attempted to summarise what I thought Sarah was communicating to check with her that I understood. I noticed that some of my questions may have appeared leading as I attempted to clarify that I understood. Existing literature reports on the challenges of interviewing those with Learning Disabilities, due to their difficulties in understanding and expression (Beail & Williams, 2014; Stigstad, 2014). In creating the semi-structured interview schedule I had considered the questions I would ask and tried to ensure that these used simple language and were not linguistically complex. I had not however tested this schedule out with someone with a Learning Disability, which with hindsight I think would have been helpful. When I created the information and consent form, this was reviewed by a group of adults with Learning Disabilities and adaptations were made following their feedback. I think it would have been beneficial to have undertaken a similar process with the interview schedule.

During the course of my research I experienced a change in field supervisor, which was a planned change in November 2014 when my original field supervisor went on maternity leave. For me, this event raised mixed feelings; happiness for my supervisor and worry about working with someone new. I had developed a supervisory relationship with the supervisor who had been involved right from the start, helping me to think about research design, sharing my worries about recruitment and attending the Social Stories group (MDT meeting) with me. I felt anxious about working with someone new, who I feared may not be as invested in the project as the supervisor who had been there from the start. Thankfully at the handover meeting between both field supervisors and academic supervisor, I saw that this was not

something I needed to worry about. My new supervisor had read all of the background information that had been shared with her and from her questions about the process it was clear that she had thought about the way the research was being undertaken. A positive supervisor relationship was quickly established and I felt relieved that the handover process had been smooth.

## **2.2 The evolving nature of the project**

Through the course of undertaking this research project, it has evolved and been adapted to meet the academic requirements of the Doctorate in Clinical Psychology. The project originally aimed to investigate whether Social Stories™ were an effective intervention for adults with Learning Disabilities and ASD. It was intended that three to four participants and their carers would be recruited and that conclusions regarding the effectiveness of the intervention would be drawn across multiple cases. However, only one case completed the study and the project had to be adapted to have a more qualitative focus so that it would constitute a Doctoral piece of research. It was suggested that the qualitative interview be fully transcribed and analysed using Interpretative Phenomenological Analysis (IPA). IPA was an appropriate method of analysis for a single case study and provided the potential to be more interpretative, unlike the Thematic Analysis already conducted on the interview notes. It was hugely disappointing for the project I had spent so much time creating and undertaking not to achieve what it had intended. It took me some time to be able to move past this feeling and to see the potential that further qualitative analysis had.

## **2.3 The analysis of experience**

### **2.3.1 Measuring participant distress**

The project had always included a qualitative element and attempted to measure the participant's distress related to the target situation, something that previous research seemed to have neglected. Gray and Garand (1993) advocate the primary aim of Social Stories™ is to reduce distress, and that any change in behaviour is an additional benefit. Finding a way to measure the very broad concept of 'distress' is a challenge, finding a measure that is suitable for a population with Learning Disabilities and ASD makes it an almost impossible challenge. People with ASD often struggle to understand

and articulate emotions and therefore trying to ask them to rate something as abstract as 'distress' is challenging for researchers and clinicians. When the study was set up, it was considered that the situation the story might target could be so varied and therefore any specific measure selected was unlikely to be suitable to all participants. Therefore it was decided to use the Patient Rated Outcome Measure, which was selected for two reasons; it was one the service used routinely to assess the outcome of professional input with service users and it could be individually tailored to any situation which the intervention might occur. Given the broad scope of situations that Social Stories™ can be used in, this was required. This measure was a 12 point Likert scale with a picture of a happy face at one end and a sad face at the other end. The scale did not have numerical values and it is possible that it was not as sensitive to the client's ratings. It could also be argued that happy and sad are not the same as distress and it may be seen as a limitation that a measure specifically created for distress in individuals with Learning Disabilities and ASD was not used. As distress is quite an abstract concept which those with ASD may find difficult to comprehend, it is a challenge to use a measure of distress that reduces the limitations noted.

### **2.3.2 Thematic Analysis**

This project may be considered unusual as two types of qualitative analysis were conducted; Thematic Analysis (Braun & Clarke, 2006) and IPA (Smith *et al.*, 2009). The project was originally designed to undertake Thematic Analysis, which was suitable to conduct across cases. As it was anticipated that multiple case studies would be recruited, it was felt most resource effective to conduct analysis from the interview notes. Previous research has conducted qualitative analysis from notes taken in interviews and it has highlighted that this method relies on the accuracy of the interviewer note taking skills (Clutterbuck *et al.*, 2009). In the present project analysis was conducted on notes taken in the interviews, which were verified and expanded through listening to the audio recording. The verifying through listening to the audio recording improved the quality of the notes and ensured that direct quotes were accurate. My 'critical realist' epistemological stance suggests our knowledge of reality is influenced by our perceptions and beliefs and meaning is communicated through a shared socially constructed language. Therefore the participant and carers language



was important, as was the meaning that they seemed to be communicating. Undertaking qualitative analysis was a relatively new experience and not something I considered myself to be very experienced in. Themes were derived inductively and there were some challenges regarding what constituted a theme. Braun and Clarke (2006) advocate that themes may be based on how frequently an idea is talked about or the strength of the comment, for example an idea might be mentioned once but feel as though it is really important. This judgement will be based on the researcher's perception, which may be influenced by what they hope to find, or perhaps what fits with previous research they have read. In the interview with the carer I was not surprised to hear her talk positively about the Social Story™, as she had mentioned how successful she felt it was during the phases of the study. I was surprised at the wider impact the Social Story™ had, as conveyed through the theme of 'deeper understanding'. To ensure that I was not over-emphasising the themes that I expected, I undertook the analysis over a period of weeks, which allowed me to have some distance from the data to return to it with fresh eyes and re-evaluate to ensure that the themes I had created were driven from the initial codes. I also used supervision to discuss the data and themes.

### **2.3.3 IPA**

The use of IPA was a post-hoc decision to expand the qualitative element of the project. Undertaking IPA was a new and daunting experience for me, as it was a method I had not previously used. Although by this point I had undertaken a meta-ethnography and thematic analysis so was becoming a little more experienced in qualitative analysis. I was apprehensive as I knew other Trainee Clinical Psychologists had had two years to learn this method and they had planned to use this from the start. I began by reading Smith *et al.* (2009), which acted as a handbook to conducting this analysis and I then went on to explore what phenomenology was and how this applied to psychology. I came to understand that phenomenology was all about each human's lived experience and the idea that in order to understand something we need to understand how someone experiences that and makes sense of it (Finlay, 2011; Langdridge, 2007). I thought about the layers of sense making, the way in which the interviewee makes sense of their experience and then the researcher attempts to

make sense of the interviewee's sense making, creating a double hermeneutic (Smith *et al.*, 2009). At the start of the analysis I wondered how Sarah and Michelle's joint sense making further complicated this. By the end of the analysis, I had come to interpret their joint sense making and incorporate this into the theme of 'co-constructing meaning', which was understood as helping to strengthen their relationship.

The quality and validity of the IPA was important and so reflexivity was engaged before and throughout the analysis and write up. I carried out a reflexive exercise before I commenced analysis, this involved asking myself:

-who am I and how might this affect the analysis?

-what is my previous experience with qualitative research and how might that affect the analysis?

-what are my assumptions of the participant and carer's experience of using a Social Story™?

Through this exercise I was able to note my pre-existing ideas that might impact on the analysis, such as my experience as a clinician using Social Stories™ which seemed to be effective and the understanding I had already developed about Sarah and Michelle's experience from the Thematic Analysis. The ongoing discussions in supervision helped me to take a step back from the data and to think about new and different interpretative ways of looking at the data. Throughout the process of analysis there were many conversations about ensuring that the interpretations we were making were evidenced in the data. Smith *et al.* (2009) outline six steps of IPA but highlighted that analysis is not a linear process, but often a more circular process and this was something I noticed within my own IPA. The process of developing the emergent themes certainly went through a back and forth process of developing themes and then almost completely discarding those themes and going back to the data to see if those ideas were really within the data. Later at the write up stage I continued to tweak the analysis, altering a few of the theme titles again to ensure that they fully reflected the interpretations I had made.

During the analysis I was acutely aware that the semi-structured interview schedule had not been developed with the intention to carry out IPA and neither had the way in which I had interviewed Sarah and Michelle. I found myself wishing I had asked them to expand on what they had meant at various points. I also noticed during the process of reading and re-reading the transcript that I as a researcher had very much subscribed to the cognitive behavioural ideas that suggested that the Social Story™ had helped with information processing. This was evident to me in the questions that I asked and also in the questions I failed to ask.

### **3. HOPES FOR FUTURE RESEARCH**

This research project was my first piece of clinical research using NHS participants. The project initially aimed to investigate if Social Stories™ were a helpful intervention for adults with Learning Disabilities and ASD, but evolved to become a focus on the experience of using a Social Story™. The qualitative analysis highlighted some interesting ideas about the possible relational aspects of using a Social Story™ and I am interested in continuing to explore whether these processes occur in other participants and their carers.

My first qualified post will be in a Learning Disability Service and I hope to have the opportunity to continue research into this area. I would like to conduct this study again, as it was not successful in exploring its initial aims to explore whether Social Stories™ are an effective intervention for adults with Learning Disabilities and ASD and there is still not enough published evidence to begin to draw conclusions about their effectiveness. Although anecdotally clinicians I have worked with can give many examples of when they have been really successful. Learning from my experience I will strongly consider making changes to the inclusion and exclusion criteria; particularly in relation to the potential participant's scores on the HONOS LD. The reasons for low referral rates need to be investigated and it needs to be considered whether strategies need to be put into place to manage these. This research project highlighted the importance of understanding the participant and carer's experience of using the Social Story and this qualitative element could be expanded to use IPA instead of thematic analysis. Intending to carry out IPA from the start would change the way in which the

interview schedule is created and I would like to trial the interview with people with Learning Disabilities to ensure that it is understandable.

The literature review and research project have left me with questions. These questions include what are families' experiences in the UK of having a family member with autism, are Social Stories™ an effective intervention for adults with Learning Disabilities and ASD, how do participants and carers experience using a Social Stories™ and does this tell us about the psychological process that are occurring when using the intervention and are these different for familial and paid carers.

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# Appendices

*Appendix A: Epistemological stance and explanation for selection of Meta-ethnography as a method of synthesis*

This researcher takes the view that there is no ultimate “truth” that can be scientifically tested and proven. Knowledge is something that is largely socially constructed; for example our ideas around what is appropriate behaviour are derived from the cultures that we are part of. The social construction of knowledge is conveyed and communicated through socially constructed language. This language contains shared words, which many people understand to mean the same thing. For words that name a physical entity which can be seen by people, it is usually assumed that the people present are seeing the same physical item. Therefore those people can be fairly certain that they are talking about the same physical item they have a shared word for. For concepts that are invisible, it is more difficult to know whether the word we use means the same to all individuals using it. Dictionaries provide definitions of words so that we can be more certain that the words we are using have the same meaning to each of us. For more complex concepts, it becomes necessary to provide lengthy explanations of what we mean. For each individual the meaning that they take from our language is tinted through the lens of their own experience, which makes it challenging for us to take the same meaning and knowledge as another person. The researcher’s epistemological stance can be situated within the context of psychological literature and common understandings of the spectrum of epistemology. The phrase often used in psychology literature to encapsulate the epistemological stance that the researcher describes is that of ‘critical realism’ (Barnett-Page & Thomas, 2009).

A number of methods of synthesising qualitative research were explored in Barnett-Page and Thomas’ (2009) paper, which compared and contrasted these methods. Some methods were more focused on comparing interventions (Ecological triangulation), using large bodies of mixed methods evidence (Critical Interpretive Synthesis), focusing on informing policy (Meta-narrative) or focused on comparing methodology (Meta-study). None of these methods were appropriate to the question this research was seeking to explore. It was felt that Grounded Theory synthesis was not appropriate as it seeks to develop a theory, which did not fit with the aim of the present paper (Barnett-Page & Thomas, 2009).

Initially the researcher considered the terms meta-synthesis and meta-ethnography to be inter-changeable terms which referred to the same type of synthesis. Through further reading it became apparent that this was a common misconception (Thorne *et al.*, 2004). Thorne *et al.* (2004) compared the author's different methods of meta-synthesis. This researcher concluded that Noblit and Hare's (1988) meta-ethnography approach was the most suitable for the current project as the goal of the synthesis was to "enlarge and enrich human discourse" and was not concerned with finding one "truth", which fitted well with the researcher's own epistemological stance (Thorne *et al.*, 2004).



Appendix B: Meta-ethnography process

Table 1. Meta-ethnography phases taken from Noblit and Hare (1988) and corresponding sections of this paper

Phase	Meta-ethnography process	Corresponding section of this paper
1	<i>Getting Started:</i> Selecting a worthwhile area of interest	2 Introduction
2	<i>Deciding what is relevant to the area of interest:</i> all possible relevant literature should be searched and what it relevant should be decided. Deciding what is relevant includes thinking about what is credible.	3.3 Literature searching
3	<i>Reading the studies:</i> repeated reading of selected articles and noting of interpretative metaphors.	3.4 Data extraction and analysis
4	<i>Determining how the studies are related:</i> listing key metaphors, phrases and concepts used in each paper and beginning initial thoughts about how studies are related to each other.	3.4 Data extraction and analysis
5	<i>Translating the studies into one another:</i> through the use of reciprocal translations, refutational synthesis and lines of argument synthesis.	3.4 Data extraction and analysis
6	<i>Synthesising translations:</i> bringing together different syntheses, making a whole from the parts and analysing competing interpretations.	3.4 Data extraction and analysis
7	<i>Expressing the synthesis:</i> presenting the findings in a language familiar to the audience you are presenting to.	4. Results

### Appendix C: Explanation of Search Terms used

The scoping searches explored the range of possible search terms and selected the terms that would yield the most relevant research. The search terms selected were 'Autism', 'famil\*' and 'experience'. The term 'autism' was used as literature related to this client group commonly used 'autism' as a keyword. Where the term 'ASD' was used, this was usually in conjunction with 'autism'. The term 'famil\*' was used to find information relevant to the subject group examined in the literature review question. Boolean logic was used and the term 'famil\*' was used with the truncation searching symbol of an asterix to include alternative endings to the search term, such as 'family' and 'families'. The term 'experience' was selected as the scoping search showed that this term yielded the most relevant literature to answer the research question.

Table 2. Database Searches

Database	Search Terms	Number of Articles yielded	Number of Articles short-listed
PsychINFO	Autism AND famil*	412	28
	Autism AND experience	27	2
Scopus	Autism AND famil*	504	21
	Autism AND experience	117	9
Medline	Autism AND famil*	29	3
	Autism AND experience	2	0
Total number of articles found		1091	
Total number of articles initially shortlisted		63	
Number shortlisted after duplicates removed		41	
Number shortlisted after more thorough screening		11	
Number of articles found by manually searching reference lists		1	
<b>Total number of articles to be quality appraised</b>		<b>12</b>	

#### Appendix D: Short-Listed Articles

Table 3. Summary of shortlisted articles that were quality appraised

Author and Date	Title	Summary	Included/Excluded?
Cassidy <i>et al.</i> (2008)	Preschoolers with autism spectrum disorders: The impact on families and the supports available to them	Used mixed methods to look at the demographics of families with pre-schoolers diagnosed with ASD, the parent's perceptions of their child's difficulties, the impact the child has on family life and the support available.	<b>Excluded</b> through quality appraisal as no specific qualitative data analysis was undertaken.
DeGrace (2004)	The Everyday Occupation of Families With Children With Autism	Interviewed five families about their daily experiences of having a child with severe autism.	<b>INCLUDED</b>
Hines <i>et al.</i> (2014)	The stories of older parents of adult sons and daughters with autism: A balancing act	Qualitative study of the lived experiences of older parents of adults with autism.	<b>INCLUDED</b>
Margetts <i>et al.</i> (2006)	Families in a state of flux: The experience of grandparents in	Qualitative study of what it is like to be the grandparent of a child with autism.	<b>INCLUDED</b>

	autism spectrum disorder		
Mascha and Boucher (2006)	Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD	Qualitatively explored the experiences of children/teenagers with a sibling who had ASD.	<b>INCLUDED</b>
Mouzourou <i>et al.</i> (2011)	At home with disability: One family's three generations narrate autism	Qualitatively explores the experiences of one family in Cyprus with a family member with Autism.	<b>Excluded</b> following quality appraisal due to the meaning that may have been lost in translation.
Myers <i>et al.</i> (2009)	"My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives	Online qualitative study exploring how having a child with ASD had affected their lives.	<b>INCLUDED</b>
Petalas <i>et al.</i> (2009)	"I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder	Qualitative study of the perceptions of eight typically developing children in middle childhood with a brother with ASD.	<b>INCLUDED</b>

Petalas <i>et al.</i> (2012)	The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder	This study qualitatively explored adolescent sibling's experiences of their brother with ASD.	<b>INCLUDED</b>
Sage and Jegatheesan (2010)	Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell	This study used multiple qualitative methods to explore two sibling's experience of having a brother with autism.	<b>Excluded</b> following quality appraisal due to the meaning that may have been lost in translation.
Tozer <i>et al.</i> (2013)	Continuity, commitment and context: Adult siblings of people with autism plus learning disability	Qualitatively investigated sibling's experiences of life with their autistic sibling.	<b>INCLUDED</b>
Woodgate <i>et al.</i> (2008)	Living in a world of our own: The experience of parents who have a child with autism	Qualitative exploration of the lived experiences of parents who had an autistic child.	<b>INCLUDED</b>

### Appendix E: The development of the Adapted Quality Appraisal Tool

There is much debate about whether quality appraisal is appropriate for qualitative research. There are arguments that validity and reliability should be assessed when reviewed qualitative studies (Hannes, 2011) and counter arguments that it is inappropriate to apply concepts such as validity to qualitative research (Hannes *et al.*, 2010). Some research has found that excluding or including qualitative research on the basis of quality makes little difference to the outcome of the review (Carroll *et al.*, 2012). Noblit and Hare (1988) do not make a specific reference to quality appraising the articles generated by searching.

For this paper it was felt that some appraisal of the quality of the papers was appropriate and that descriptive validity, interpretative validity and theoretical validity were all important constructs (Hannes *et al.*, 2010). Hannes *et al.* (2010) compared and contrasted three commonly used, easily accessible quality appraisal tools; the Joanna Briggs Institute Tool (JBI), the Critical Appraisal Skills Program Tool (CASP) and the Evaluation Tool for Qualitative Studies (ETQS). They concluded that all tools had merits (Hannes *et al.*, 2010).

For the purposes of this meta-ethnography the researcher developed a quality appraisal tool, referred to as the Adapted Quality Appraisal Tool. It took questions from all three tools which were felt to be relevant to the area of research being investigated. The underlying idea of congruence between the aims, epistemology and methodology was taken from the JBI tool, along with the ideas around the participant's voices being heard. The idea of appropriate recruitment, rigorous data analysis and accounting for ethical issues were taken from the CASP Tool. Ideas around the impact of the researcher and the conclusion being justified were adopted from the ETQS. The Adapted Quality Appraisal Tool made room for descriptive answers to be written so that quality could be fully assessed. The researcher then used her judgement to exclude articles on the basis that they did not display quality in a number of areas.

Appendix F: Adapted Quality Appraisal Tool

**Adapted Quality Appraisal Tool**

1. Were the research aims clear?	
2. Was the design methodology clearly explained and appropriate to the question(s)?	
3. Was the recruitment strategy appropriate to the research question(s)?	
4. Was the data collected in a way which was congruent with the research question(s)?	
5. What data analysis was used? Was the data analysis sufficiently rigorous?	
6. Is there a clear statement of findings?	
7. Are the participants and their voices heard?	
8. Have ethical issues been taken into account?	
9. Has the impact of the researcher on the participants been adequately considered?	
10. Is the conclusion justified given the conduct of the study?	

### Appendix G: Summary of the quality appraisal findings for included articles

*Research aims and design methodology:* All papers were explicit about their research aims and clearly explained their methodology. All papers made the link between participant experiences and therefore choosing qualitative methods. A few of the papers made reference to the reasons for selecting their particular qualitative methodology.

*Participant Recruitment:* All papers used methods of recruitment which targeted the population which they sought to investigate. Many of the studies applied inclusion criteria to ensure that they only selected relevant participants, for example ensuring the relative had a formal diagnosis of ASD.

*Data collection and analysis:* All but one paper (Myers *et al.*, 2009) used semi-structured interviews as a way to collect data. All commented on the use of open-ended questions. Myers *et al.* (2009) used an online survey with an open-ended question. A range of methods of data analysis were used; Interpretative Phenomenological Analysis (Petalas *et al.*, 2009; Petalas *et al.*, 2012), Phenomenological Analysis (DeGrace, 2004), Content Analysis (Mascha & Boucher, 2006); Myers *et al.*, 2009), Narrative Analysis (Hines *et al.*, 2014); (Tozer *et al.*, 2013), Selective Highlighting Approach (Woodgate *et al.*, 2008) and General Inductive Method (Margetts *et al.*, 2006). Researchers also used a number of methods of ensuring that their analysis was rigorous enough. For example multiple researchers conducting analysis so that they could confer (DeGrace, 2004; Margetts *et al.*, 2006; Myers *et al.*, 2009; Petalas *et al.*, 2009; Petalas *et al.*, 2012), keeping reflective diaries (DeGrace, 2004) and sharing their analysis with participants to verify accuracy (Hines *et al.*, 2014; Margetts *et al.*, 2006; Tozer *et al.*, 2013).

*Findings:* All papers had a clear statement of findings, used rich descriptions and participant quotes to demonstrate their themes.

*Ethical issues:* All but one paper (Mascha & Boucher, 2006) stated that their research had been approved by an ethics committee.



*Impact of the researcher:* A number of papers commented on the impact the researcher may have had on either the data collection or analysis (DeGrace, 2004; Margetts *et al.*, 2006; Mascha & Boucher, 2006; Petalas *et al.*, 2009; Petalas *et al.*, 2012).

*Conclusion:* All papers linked their findings to the evidence base. None drew conclusions that were not justified or based in their own findings.

Appendix H: Data extraction from nine articles included in meta-ethnography

Table 4.1 Sample, Methodology and Key Themes of articles synthesised in meta-ethnography

DeGrace, (2004)	Hines <i>et al.</i> , (2014)	Margetts <i>et al.</i> , (2006)
5 families consisting of 2 parents and 2 children (1 of which had autism)	16 parents of 13 adults with autism	6 grandparents; 3 grandmothers and 3 grandfathers
In-depth interviews Phenomenological analysis	In-depth interviews Structural analysis, thematic and performative analysis, comparing and contrasting across participants	Semi-structured interviews General inductive method of analysis
Life revolves around autism – “your whole family’s life is always revolving around this situation” pp.546  ‘accrued stress’ – “it just constantly builds up” pp.546  Limited shared activities – “we’d rather do a lot more” pp.547  no ‘time away from autism’, “we deserve some time to relax” pp.547  robbed of “inner satisfaction” pp.546  ‘occupy and pacify’ pp.547  ‘fleeting moments’ of “feeling like a family” pp.547	Treading a fine line balancing everyone’s needs, survival depends on it – “burden of trying to do the right thing by the other kids as well as [our son with autism]” pp.168  ‘regimented’ lives are a necessity pp.168 – parents belief that autistic child prefers routines and challenging them will lead to ‘overwhelming’ consequences and interfere with the child’s emotional wellbeing  Battling the system – “I have fought them tooth and nail” pp.170, interaction with services is an ‘extension of older adults balancing acts’	Feeling responsible - “I must look out for all the family” pp.571  Supporting but not undermining – “I’ve been involved from the word go” pp.570, “now I think my daughter is able to take over” pp.571  ‘tolerate’ not knowing the cause of autism pp.571  the ‘parental bond’ – “our worries were not just for our [granddaughter], but also for [son] and [daughter-in-law]” pp.569  ‘permitting favouritism’ – “I love him best of all” pp.569

Table 4.2 Sample, Methodology and Key Themes of articles synthesised in meta-ethnography continued

Mascha & Boucher (2006)	Myers <i>et al.</i> , (2009)	Petalas <i>et al.</i> , (2009)
14 siblings; 10 sisters and 4 boys aged 11-18 years	493 parents (92.2% mothers)	8 siblings; 3 brothers and 5 sisters aged 9-12 years
Semi-structured interviews using open questions Content analysis	Web-based questionnaire, one open question analysed Content analysis	Semi-structured interviews IPA
<p>Positive experiences – playing and having fun, siblings’ good nature and sibling being happy</p> <p>Challenges – aggression “she gets angry” pp.22; “embarrassing” pp.22; responsibility “I have to help mum more” pp.22; “trying to explain what his problem is” pp.23</p> <p>Understanding makes things easier – “my parents spent a lot of time telling me about it... it made it a lot easier to understand why” pp.23</p> <p>Future worry – “I get scared” pp.23</p>	<p>“The stress is constant” pp.674</p> <p>“totally burned out” pp.677</p> <p>Restricted by autism – “we are ruled by his fixations” pp.675, “our entire lives revolve around autism” pp.679, “there are some things that we do not even attempt” pp.680</p> <p>Exhaustion – “we are always tired” pp.676</p> <p>Fighting services – “we have had to fight for everything we’ve gotten for him” pp.676</p> <p>Unconditional love – “I love him no matter what’s wrong” pp.679</p> <p>“marriage is strained”, “no time together” pp.677</p> <p>“ruined us financially” but “worth every penny” pp.679</p> <p>Personal growth – “we learned not to take things for granted” pp.678</p> <p>Siblings get “the short end of the stick” pp.679</p> <p>“made our family stronger”</p>	<p>Aggression – “don’t wind him up, he’ll hurt you” pp.387</p> <p>Living in a “madhouse” pp.388</p> <p>“it can affect me”, “irritated”, “angry” pp.387</p> <p>Social judgement – “they don’t see Jack for who he really is” pp.388</p> <p>2 ways of dealing with others – “you tell them more about it” or “don’t really speak about it” pp.388</p> <p>Acceptance vs wanting change – “I like him the way he is”, “make him a normal person” pp.390</p> <p>Shared “fun” pp.390</p> <p>Pride – “doing so well” pp.391</p> <p>Support by talking to others who “understand it better” pp.392</p>

	<p>pp.680</p> <p>Judgements and blame –  “they believe that I caused  my son’s autism pp.680,  “I’ve heard all the remarks”  pp.681</p>	
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Table 4.3 Sample, Methodology and Key Themes of articles synthesised in meta-ethnography continued

Petalas <i>et al.</i> , (2012)	Tozer <i>et al.</i> , (2013)	Woodgate <i>et al.</i> , (2008)
12 siblings; 6 brothers and 6 sisters aged 14-17 years	21 adult siblings; 14 sisters and 7 brothers aged 25-67 years	21 parents; 16 mothers and 5 father (included 5 couples)
Semi-structured interviews IPA	Semi-structured interviews Narrative analysis	In-depth interviews Selective highlighting approach
<p>Aggression – “violent” pp.307</p> <p>Sympathy vs irritation – “something in there making them do it” pp.307</p> <p>Parent’s “battle” pp.307</p> <p>Social judgement – “they just don’t understand” pp.308, “embarrassing” pp.307, “you pretend no-one’s looking” pp.308</p> <p>Enjoyment – “fun”, “spend a lot of time together” pp.308</p> <p>Admiration and acceptance – “he’s really quite remarkable” pp.310, “it’s kind of cool that he’s different” pp.309</p> <p>Hope vs worry – “I just want it to be okay for him” pp.310, “I just want him to be happy” pp.309, “worries” that he might get “worse and worse” pp.310</p>	<p>Home life which “revolved around autism” pp.438</p> <p>‘inhabiting two worlds; one at home where disability was the norm and the outside world where it was not’ pp.483</p> <p>Carer- “I took charge, when I realised he needed help” pp.483</p> <p>Close bonds and hard work – “I love him to bits... but then a lot of the time you think this isn’t rewarding” pp.484</p> <p>Balancing commitments and feeling “guilty” – ‘constantly (re)negotiating a range of competing family obligations’ pp.485</p> <p>Invisible to professionals – “professionals weren’t really interested in me” pp.485</p> <p>“I’m totally dedicated to her welfare” pp.485</p>	<p>“Living in a world of our own” pp.1078</p> <p>“stigmatized” pp.1078 – lack of understanding</p> <p>“no life” pp.1078 – isolated from friends and family</p> <p>Fighting an ‘inaccessible’ system</p> <p>‘vigilant parenting’ pp.1079</p> <p>“working towards a healthy balance” pp.1080, ‘take time away’</p> <p>‘cherishing different milestones’ and “accomplishments”</p>

### Appendix I: Understanding Autism

Wing and Gould's (1979) triad of impairments is often used as a way of conceptualising the difficulties people with ASD experience. The model highlights the common areas of difficulty in three domains; language and communication, social awareness and interaction, and lack of imagination and rigidity of thought (Wing & Gould, 1979).

Those with ASD often present with rigidity of thought, sticking to rules and the familiar. They struggle to understand the subtleties of social interaction, particularly non-verbal communication and unspoken social etiquette. This makes it difficult for them to comfortably interact with others, especially in new, or with unfamiliar situations and people (Ali & Frederickson, 2006). It may also cause them distress and at times to behave in a way that is socially inappropriate or unacceptable, for example aggressive or self-injurious behaviour (Church, *et al.*, 2000). There are a number of theories which attempt to explain the difficulties people with ASD experience.

Baron-Cohen (1995) posed that these difficulties with social functioning and understanding could be attributed to 'mindblindness'. 'Mindblindness' is the inability to understand another person's internal mental states and use this understanding to interpret behaviour. Baron-Cohen proposes a number of internal mechanisms that humans develop over infancy which support the ability to interpret other's mental states. The first is the 'Intentionality Detector' which ascribes intention to any moving object seen, the second is the 'Eye-Direction Detector' which helps us to notice another's eye movements and guess what others are seeing, the third is the 'Shared-Attention Mechanism' which allows us to use our eyes to direction another's attention to an object. These three mechanisms are all required for the 'Theory of Mind Mechanism' which enables humans to infer mental states from behaviour. So our ability to know that movement has intention, to see what others are looking at and to jointly attend to a stimulus, helps us to better guess what other people thinking. Baron-Cohen suggests that people with autism have an impaired 'Shared-Attention Mechanism' which impacts detrimentally on the 'Theory of Mind Mechanism'. Therefore those with ASD are unable to distinguish between their own beliefs and what other's may believe. Baron-Cohen's theory of 'mindblindness' has a robust supporting evidence base (Baron-Cohen, 1995; Frith & Hill, 2003).

An alternative theory is Frith's central coherence theory which suggests that there are differences in the way that people with ASD process information. This theory suggests that most people will process information in a broader sense, taking in contextual factors to interpret a higher level meaning, such as taking in the 'gist' of a story. However those with ASD will take a more detailed approach, focusing on specifics and excluding context, for example remembering specific details of a story rather than the 'gist' of the story (Frith & Hill, 2003).

**Learning Disabilities Team Logo**

**NHS Trust Logo  
Team Address  
Team Contact details**

**Details removed to maintain service confidentiality**

**The Social Stories Research Project Referral Form**

Thank you for thinking about referring one of your service users to the Social Stories Research Project.

You must have consent from the service user and their carer to refer them to this study and to be contacted by the researcher to hear full details of the study. Please tick to confirm you have done this.

☐

In order to ensure that your service user meets the criteria for the study, please complete the following checklist:

- ☐ Is the service user 18 years or over?
- ☐ Have they been assessed as having a Learning Disability?
- ☐ Do they have diagnoses of Autism or Aspergers Spectrum Disorder?
- ☐ Can they communicate verbally in simple sentences and understand and follow simple instructions?
- ☐ Do they have a score of two or below on the HONOS LD on aggression towards others?
- ☐ Do they have a score of one or below on the HONOS LD on aggression towards self?
- ☐ Do they have a simple behaviour problem that occurs regularly and may lend itself to being addressed by a social story?
- ☐ Do they have a consistent person involved in their care (such as staff or family) who would be willing to carry out intervention and keep records of this?



- ☐ Is there a professional from the Learning Disability Service is involved in their care and who has assessed their needs and has some understanding of the cause of the behaviour to be addressed?
- ☐ Does the service user have the ability to give consent?

The following items are exclusion criteria for the study. Please can you check that none of these apply to the service user:

- a) Are they Engaging in another active intervention (not including medication which is at a consistent dose)?
- b) Do they have any additional mental health problems, e.g. psychosis, depression?
- c) Do they have any additional substance misuse problems?

If any of these apply then they will not be eligible to participate, so please do not refer them to the study.

If your service user meets the criteria for the study then please fill in the following details:

<b>NAME OF REFERRER:</b>	<b>PROFESSION:</b>
<b>CONTACT ADDRESS:</b>	<b>CONTACT NUMBER:</b>
	<b>EMAIL ADDRESS:</b>
<b>NAMED PROFESSIONAL IN THE LEARNING DISABILITY SERVICE:</b>	<b>PROFESSION:</b>
<b>CONTACT ADDRESS:</b>	<b>CONTACT NUMBER:</b>
	<b>EMAIL ADDRESS:</b>
<b>SERVICE USER NAME:</b>	<b>SERVICE USER DATE OF BIRTH:</b>
<b>SERVICE USER ADDRESS:</b>	<b>CONTACT NUMBER:</b>
<b>CARER NAME:</b>	<b>RELATION TO THE SERVICE USER:</b>
<b>CARER ADDRESS:</b>	<b>CONTACT NUMBER:</b>

**BRIEF DESCRIPTION OF THE BEHAVIOUR TO BE ADDRESSED BY THE SOCIAL STORY™:**

.....  
.....  
.....

Referrer Signature: ..... Date: .....

Please return to Dr \*\*\*\*\*, Clinical Psychologist at *Service Address removed for confidentiality*.

If you have any questions about this study or whether your service user meets the criteria, please contact Nicol Aphalé (Trainee Clinical Psychologist) at [na87@le.ac.uk](mailto:na87@le.ac.uk) or Dr \*\*\*\*\* at [\\*\\*\\*\\*\\*@\\*\\*\\*\\*\\*.nhs.uk](mailto:*****@*****.nhs.uk) , Tel: 0\*\*\*\*\*

Appendix K: Behavioural monitoring form

**Learning Disabilities Team Logo**

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**Team Address**  
**Team Contact details**

**Details removed to maintain service confidentiality**

Name: \_\_\_\_\_

Situation: \_\_\_\_\_

Completed By: \_\_\_\_\_

**Behaviour Definitions:**

- 1.
- 2.
- 3.
- 4.
- 5.

<b>Date and Time Period</b> <i>e.g. Monday 10<sup>th</sup> March, 10am – 10.30am</i>	<b>Behaviours</b> <i>Please tick every time these behaviours occur.</i>					<b>Any other observations or comments</b>
	<i>Insert behaviour</i>	<i>Insert behaviour</i>	<i>Insert behaviour</i>	<i>Insert behaviour</i>	<i>Insert behaviour</i>	

Appendix L: Patient Rated Outcome Measure (PROM)

**Learning Disabilities Team Logo**




**NHS Trust Logo  
Team Address  
Team Contact details**

*Details removed to maintain service confidentiality*

**Outcome measures were agreed with (tick):**

- ☐ **service user**  
☐ **carer (Name and relationship: \_\_\_\_\_ )**

**What are the issues that we have agreed to work on?**

<b>Issue/Problem</b>											
Description											
Record the question you have asked about <i>rating</i> the issue here:											
											

### Appendix M: Social Stories™ Project; Semi-Structured Interview Schedule

These questions formed the basis of the semi-structured interview at the end of the maintenance phase of the research. The focus of this semi-structured interview was to find out about the participant and carer's experience of the Social Story™ intervention. The semi-structured interview aimed to last 20 to 30 minutes.

#### **Questions for Carers**

1. Tell me how you have found the Social Story™.
2. Were there any changes to their behaviour?
3. Are there any things that could have made it easier to use?
4. Is there anything you would change?
5. Do you think you would use a Social Story™ again?
6. Is there anything else you would like to tell me?

#### **Questions for Participants**

1. How did you find the Social Story™?
2. What did you like about it?
3. What did you not like about it?
4. Do you think it was helpful?
5. Is there anything else you would like to tell me?

## Appendix N: Detailed outline of the study procedure

### 1. Gaining informed consent and setting up the study

Following referral by a professional, the carer and service user were contacted via telephone to further explain the study. A meeting was arranged to share further details using the Information and Consent Forms (Appendices O, P and Q). Consent was sought if the problem seemed as though it could be helped by a Social Story™. A target situation and associated behaviours were selected and the service user rated how they felt about the situation using the PROM. The carer was given Functional Analysis Behaviour Recording Forms (see Appendix R) to record details around the antecedents and consequences to the behaviours in the target situation for two weeks. Existing research has suggested that Social Stories™ are more effective if they address the function of the behaviour (Cihak *et al.*, 2012).

### 2. Baseline Phase and Social Story™ creation

The researcher met with the carer once two weeks of Functional Analysis recordings had been completed. The information gathered was discussed with the carer to further explore the causes of the participant's behaviour in the target situation and to develop a psychological formulation. Target behaviours (both undesired and appropriate behaviours) were defined. These conversations also gathered information about the target situation which was used to inform the Social Story™. The individually tailored behaviour recording form was completed with the defined behaviours for recording and given to the carer to commence recording for the Baseline Phase. The Baseline Phase was ten occurrences of the target situation.

During the Baseline Phase the researcher created the Social Story™ using the most recent version of the manual and the information received at Gray's Social Stories™ training course (Gray, 2010 & 2014). Input from Speech and Language Therapists was sought regarding the pictures used. The Social Story™ was then shared with the field supervisor for further input and modifications were made. The Social Story™ was shared with the participant and carer at the end of the Baseline Phase to ensure that it

was understood. In all cases the participant and carer reported that the Social Story™ was understood and no further adjustments were required.

### 3. Intervention, Fade and Maintenance Phases

The Social Story™ was given to the carers with instructions to read the story between 30 minutes and 90 minutes prior to the target situation for 20 consecutive occurrences of the target situation. In the fade phase the Social Story™ was read to the participant at a reduced frequency of every other occurrence of the target situation, for 20 occurrences. In the maintenance phase participants and their carers' were given the option of having the Social Story™ available for the participant to read/request for it to be read or negotiating a further reduced frequency of reading. It has been observed that many people with ASD find change difficult and prefer to have a routine so that they know what to expect (Wing & Gould, 1979). Therefore participants and carers were given the option to retain some of the structure of reading the Social Story™ if this was their preference. The maintenance phase lasted for 20 occurrences of the target situation. The same behaviour recording form was used to monitor the frequency of the defined undesired and appropriate behaviours throughout all phases.

### 4. Outcome and Interviews

On completion of the maintenance phase the researcher collected all of the behaviour recordings and created a simple graph to share with the participant and carer. This graph indicated the frequency of all undesired and appropriate behaviours throughout the study. The researcher met with the participant and carer for a final meeting. In this meeting the simple graph was shared, the PROM was completed and interviews were conducted with the participant and carers. The participant and carer were given the option to have their interviews separately or together to ensure that both felt comfortable. Interviews were audio recorded, with their consent.



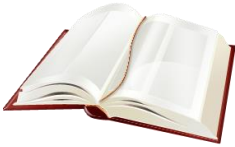

Appendix O: Participant Information and Consent Form

**Learning Disabilities Team Logo**

**NHS Trust Logo**  
**Team Address**  
**Team Contact details**

**Details removed to maintain service confidentiality**

**The Social Stories Project**

	Nicol is doing a project as part of her training to be a Clinical Psychologist.
	Nicol wants to find out if Social Stories help people with Learning Disabilities and Autism Spectrum Disorders.
	A Social Story is a short story which helps you to change your behaviour.
	<p>An example: If someone shouts a lot in a café they will be asked to leave.</p> <p>A Social Story would tell them to sit quietly and have their drink. They would be able to stay in the café.</p>





Nicol will meet with you to see if a Social Story is right for you.

She will ask you some questions.



Your carer must also want to take part in the project.



You and your carer will pick one thing that you do that you want to change. This is called a behaviour.



Your carer will watch your behaviour.

They will write down what you do.



Your carer will read you a Social Story about the behaviour.



Your carer will read the Social Story to you lots of times so you can understand what it means.



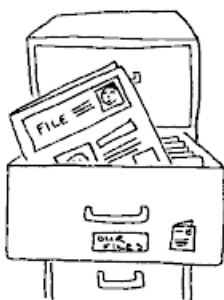
Your carer will carry on watching what you do and write things down.

This will tell us if the story helps you.



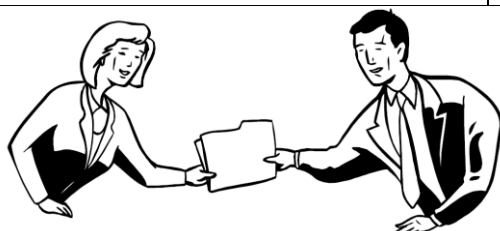
Nicol will ask you and your carer to come back to see her.

She will ask you questions to see what you thought about the Social Story.



Every time Nicol meets with you or your carer, she will write some things down.

The notes will be kept in a safe place, locked away.








Nicol will tell your doctor and others who help you that you are taking part in this project.





Nicol will tell other people in the service about your Social Story. Nicol will tell them whether it helped you and what you said about it.

Nicol will not tell them your name.

	<p>Nicol may also write about the Social Story in one of the books or magazines that are made for professionals. Again, she will not write your name.</p>
	<p>If you are upset during the study, you can talk to your carer, Nicol or your keyworker  <u><i>Insert keyworker name</i></u></p>
	<p>If you want to stop doing the project at any time, just tell Nicol.</p> <p>You do not have to do the project if you do not want to.</p>
	<p>If your carer does not want to do the project then you will not be able to.</p>
	<p>If you want to talk to someone about the project then you can call the Patient Advice and Liaison Service (PALS) on 01*****.</p>

**Do you want to take part in this project?**

<b>I want to take part</b>	<b>I do NOT want to take part</b>
<input type="checkbox"/> 	<input type="checkbox"/> 

**Your Name:**.....

**Name of person supporting you:**.....

**Name of Researcher:** .....Nicol Aphale.....

**Date:**.....

**Learning Disabilities Team Logo**

**NHS Trust Logo  
Team Address  
Team Contact details**

**Details removed to maintain service confidentiality**

**Title of Research:** Are Social Stories™ an effective intervention for adults with Autistic Spectrum Disorders (ASD) and Learning Disabilities (LD).

**Researchers:** Nicol Aphalé (Trainee Clinical Psychologist), supervised by Dr \*\*\*\*\* (Clinical Psychologist in the Learning Disability Service) and Ms Mary O'Reilly (Senior Clinical Tutor at University of Leicester)

**We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. The researcher will go through this sheet with you and answer any questions you might have.**

This research project is being undertaken by Nicol Aphalé, a Trainee Clinical Psychologist at the University of Leicester. The project is part of her Doctorate in Clinical Psychology qualification.

**What is this project about?**

A Social Story™ is an individually created story to help an individual understand a situation and so reduce their distress and challenging behaviour. This intervention was created to be used with Autistic children and research shows that it is effective. At present there are a few studies which show that this intervention could also be effective with adults with Autistic Spectrum Disorders (ASD), Learning Disabilities (LD) and Development Disabilities.

This project aims to investigate whether Social Stories™ are an effective intervention for adults with ASD and LD. It aims to find out whether Social Stories™ reduce challenging behaviour and distress, whilst increasing positive behaviour. It also aims to find out the individual and carer's experience of the intervention.

### **Why have I been invited to participate?**

You are the carer of a person with diagnoses of ASD and LD. This person has been referred to the study as a Social Story™ might be a suitable intervention for them. Social Stories™ are routinely used in the Learning Disabilities Community Team. This research seeks to find out whether they are effective. Participation is voluntary. Both you and the person you care for must agree to participate to be involved.

### **What if I don't want to be part of the study?**

If after reading this information and talking to the researcher you decide that you do not want to be involved in this study, then you do not have to be. This will not affect the care of the participant, who will still receive an assessment and appropriate intervention from the Learning Disability Service.

### **What will I have to do?**

There are four things which carers will need to do:

1. Meet with the researcher to talk about the participant's challenging behaviour in the target situation. Specific behaviours will be selected through discussion with the participant and yourself. For the first two weeks you will be asked to complete Functional Analysis Forms which will ask you to provide information about the behaviour that occurs in the target situation and what happens before and after the behaviour.
2. Carefully monitor the participant's behaviour in the target situation before the intervention, during the intervention and after the intervention. You will be given simple recording sheets to record when these behaviours occur in the target situation. Behaviour will need to be recorded for a total of 70 occurrences of the target situation. How long this will take will depend on how frequent the target situation is. For example, if the target situation occurs three times a day then behaviour will need to be recorded for 24 days, if the target situation occurs once a day then behaviour will need to be recorded for 2 ½ months.
3. Read the Social Story™ to the participant immediately prior to the target situation. This will be for 20 occurrences of the target situation first, then this will reduce to every other time the target situation occurs over 20 occurrences of the target situation. The Social Story™ will then be available to be read at the participant's request.

4. Participate in a short interview about the Social Story™. The researcher will ask questions about what you thought of the Social Story™ as an intervention. This will be tape recorded to help the researcher accurately record what you say.

#### **What are the disadvantages of being involved?**

You will be asked to keep very thorough recordings of the participant's behaviour and to read them to Social Story™ on a consistent basis. This may be time consuming.

When Social Stories are routinely provided by the Learning Disability Community Service, carers are asked to keep recordings but there is not such a strong emphasis on these being very thorough.

#### **What are the benefits of being involved?**

Although you will have to be very thorough in recording behaviour and reading the story, this will help you to know how helpful the Social Story™ was and what it helped with. You will also be helping add to research about what interventions are helpful or not helpful for people with ASD and LD.

#### **What if I change my mind about being involved?**

You have the right to withdraw from the study at any time, you can let the researcher know if this is the case. The researcher will also check with you throughout the study that you are happy to continue. If you withdraw from the study, the participant will still receive a Social Story™ but will not be able to participate in the study.

#### **What if there is a problem during the study?**

If at any point you are unhappy with what is happening in the study, then you can speak to the researcher. If you would like to speak to someone who is not involved in the study, or if you would like to make a complaint, then you can contact the Patient Advice and Liaison Service (PALS) on 0\*\*\*\*\*.

#### **What will be done with the information collected?**

All information will be recorded and kept anonymously. Participants and carers will be given participant numbers to help keep your identity confidential. Only the researcher, supervisor and the staff involved in the participants care will be able to see the

information collected. This research project is part of the trainee clinical psychologist's doctoral training and therefore the results will be written as a thesis and submitted to the course to be marked. In the write up all people involved will be anonymous and any potentially identifying information will be removed (such as the area you live in). The results will also be written up as paper for publication in a relevant academic journal and as a presentation for relevant conferences which other healthcare professionals read/attend. All participants and carers will remain anonymous and any potentially identifying information will be removed.

### **What will happen at the end of the study?**

At the end of the study, the researcher will meet with you and the participant to tell you what the findings showed for the person you care for.

The individual you care for will still be under the care of the Learning Disability Community Team and you will be able to discuss with their keyworker whether you require any further support.

### **Who has reviewed this study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands Northampton Research Ethics Committee.

***Please ask the researcher if you have any questions or if any of the information is not clear.***

***If you are not sure whether you want to be involved, you can contact the Patient Advice and Liaison Service (PALS) for confidential and impartial advice and guidance. Their telephone number is 0\*\*\*\*\*.***



Appendix Q: Carer Consent Form

**Learning Disabilities Team Logo**

**NHS Trust Logo**  
**Team Address**  
**Team Contact details**

**Details removed to maintain service confidentiality**

**Title of Research:** Are Social Stories™ an effective intervention for adults with Autistic Spectrum Disorders (ASD) and Learning Disabilities (LD).

**Researchers:** Nicol Aphale (Trainee Clinical Psychologist), supervised by Dr \*\*\*\*\* (Clinical Psychologist in the Learning Disability Service) and Ms Mary O'Reilly (Senior Clinical Tutor at University of Leicester)

*Please initial all boxes*

- |   |                          |
|---|--------------------------|
| 1. I confirm that I have read and understand the information provided on the Information Sheet Version..... I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without the service I receive from the Learning Disability Service being affected.                   | <input type="checkbox"/> |
| 3. I agree to take part in this study.  | <input type="checkbox"/> |
| 4. I agree to record the participant's behaviour for the duration of the study.   | <input type="checkbox"/> |
| 5. I agree to read the Social Story™ to the participant as instructed by the researcher.  | <input type="checkbox"/> |
| 6. I agree to take part in a short interview at the end of the study and for this to be recorded using a digital tape recorder.   | <input type="checkbox"/> |

_____	_____	_____
Name of Participant (Carer)	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

Appendix R: Functional analysis

PARTICIPANT NUMBER \_\_\_\_\_

COMPLETED BY \_\_\_\_\_

Time (s)	Behaviours					Predictors / Triggers									Perceived Functions							Actual Consequences		Comments					
															Get / Obtain			Escape / Avoid											
						Demand / Request	Difficult Task	Transitions	Interruptions	Alone no attention					Attention	Desired item/activity	Self-stimulation		Demand / request	Activity ( )	Person		Other / Don't know						
Event(s)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25				
Date(s)																													

## Appendix S: Section of Transcript and IPA analysis

	448	well erm... you know me burning myself and you know its not kind of	worried - fear .)
	449	what you want but it's inevitably going to happen if Sarah keeps coming in	Kitchen is dangerous, mum hurts herself (? Sarah's fault?)
	450	(.) And she knows that and its important although it's upsetting and even	Sarah is upset at the thought of mum hurting self (or at thought of being away from mum?)
	451	when I read it I see her face and she doesn't like that obviously I'm going to	
	452	drop or break something or burn myself or ermm but yeah erm I think it's	
	453	definitely in there isn't it Sarah? Going to remember the story aren't you?	
	454	S: uh huh	(hope for positive change to continue?)
	455	I: I'm glad that its been really helpful and I guess erm the kind of using it in	seeking reassurance from Sarah? checking the remembers (wanting things to be okay)
	456	the future hopefully that will continue with Tracey	
change at the right pace	457	M: oh I can think of lots of erm situations that we could we don't want to	want more stories but not too much change (? hard to let go of Sarah)
	458	be over err grounds with it	
	459	S: I'm even thinking when transport don't turn up that is one when it don't	Sarah's idea for another story
	460	turn up	
stories can help manage anxiety	461	M: mm yeah I think we could start with that... it would be a very useful	recognition that story helped Sarah manage her feelings - anxiety (is mum worried to!)
	462	one because you do get very very worried when transport is late or when	
	463	they're early (.) Maybe different ways you could deal with things yeah... to	
	464	help you so you don't get so worried yeah? So that's what erm Nicol's	
professional involvement offers containment for Michelle	465	going to speak to Tracey about to see if we can do some more stories erm	Need Tracey for more stories (reassured by Tracey's input?)
	466	for other things ... yeah? ... And I think that could definitely erm work	
	467	couldn't it? And when you get on the bus as well that's another one isn't	-another idea for a story, getting on the bus
	468	it?	
	469	S: That is another one	don't want too many stories (? too much change?)
change at the right pace	470	M: So... but we don't want lots but it's something Nicol and talk to Tracey	mentioning Tracey again (Tracey is containing in some way)
professional involvement	471	about and we can decide (.) I think you only need one at a time though I	
change at the right pace	472	don't think you need lots of stories in one go because I won't remember all	one story at a time (not wanting change?) (or to let go of Sarah?)
	473	them stories Sarah	
	474	S: No I won't	Sarah & Michelle won't remember lots of stories
change at the right pace	475	M: No alright (.) So we'll do it slowly like we did with this one the yeah?	slow pace of story important, helpful (importance of manageable change.)

#### Appendix T: Ethical Approval Correspondence

The following pages include scanned copies of the correspondence with the NRES Ethics Committee:

- Provisional Opinion letter from NRES, dated 22<sup>nd</sup> January 2014
- The researcher response, dated 24<sup>th</sup> January 2014
- Request for further details from NRES, dated 30<sup>th</sup> January 2014
- The researcher response, dated 4<sup>th</sup> February 2014
- NRES approval letter, dated 5<sup>th</sup> February 2014

Please note, all identifying information has been removed to maintain confidentiality.

# Health Research Authority

## NRES Committee East Midlands - Northampton

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 883 9440

22 January 2014

Miss Nicol Aphale

University of Leicester - Clinical Psychology Department  
104 Regent Road  
Leicester  
LE1 7LT

Dear Miss Aphale,

<b>Study Title:</b>	<b>Social Stories™ as an individually tailored intervention for adults with Autistic Spectrum Disorders (ASD) and Learning Disabilities (LD).</b>
<b>REC reference:</b>	<b>14/EM/0010</b>
<b>Protocol number:</b>	<b>R&amp;D Ref: LDIS0660</b>
<b>IRAS project ID:</b>	<b>144727</b>

The Research Ethics Committee reviewed the above application at the meeting held on 16 January 2014. Thank you for attending to discuss the application.

### Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Advertisement	Social Stories poster, V1.1	29 November 2013
Advertisement	Social Stories extended poster, V1.1	29 November 2013
Covering Letter		04 December 2013
Interview Schedules/Topic Guides	Semi-structured interview schedule, V1.1	02 December 2013
Investigator CV	N Aphale	29 November 2013
Investigator CV	Mary OR	29 November 2013
Letter of invitation to participant	Social Stories referral letter, V1.1	22 November 2013
Letter of invitation to participant	Social Stories participation letter, V1.1	29 November 2013
Other: User reported outcome measure (PROM)	1.1	29 November 2013

Other: Functional Assessment Observation Form	1.1	13 December 2013
Other: Behaviour Recording Form Template	1.1	13 December 2013
Participant Consent Form	1.2	29 November 2013
Participant Consent Form: Carers	1.1	22 November 2013
Participant Information Sheet	1.2	29 November 2013
Participant Information Sheet: Carers	1.1	22 November 2013
Protocol	1.1	11 November 2013
REC application	144727/535987/1/818	04 December 2013
Referees or other scientific critique report	Research Panel Meeting minutes	11 June 2013
Referees or other scientific critique report	Interview Peer Review Form	10 October 2013

### Provisional opinion

- The committee asked you as the IRAS form says if the carer is withdrawn from the study, the patient will still receive the intervention. How will you know they will not also want to withdraw? Is the Social Story part of standard care? You had informed the committee the Social Stories are used as an intervention anyway. If carers want to withdraw they can do this at any contact point.
- The committee commented it is likely some patients will already have the intervention. You informed the committee part of the inclusion criteria is to not be having the intervention already.
- The committee asked if the population being recruited will be living at home, or in independent living. You informed the committee this could be various and that the carer could be paid, a family member or someone who knows the patient best.
- The committee asked as the total number of participants is four, if there is withdrawal from the study, how do you propose to carry on? You informed the committee she will seek to replace these through referral meetings. If a participant decides to withdraw, she will return to referral meetings for either new patients or to see if there are people already waiting.
- The committee asked how the Visual Analogue Scale works. You informed the committee this is used within the Trust already. She will ask the individual to set a goal, and rate on the scale how they are doing. Once the intervention is complete they will be asked to re-do this.
- The committee questioned what would happen if the carer withdraws from the study but the patient wants to carry on. Would they feel isolated? You informed the committee all patients have a key worker if their carer didn't want to record the information required. The committee commented if the carer would have the best interest doing the Social Story as the ownerous will be on them completing the paperwork. It was asked if the data will be used if the carer withdraws and the patient continues, You confirmed the data will not be used. The committee commented to you this is not very clear in the Participant Information Sheet. For patients the link between themselves and their carer is very important.

- The committee commented if a family member is a carer, this could cause stress with the family. You informed the committee the goals will be set by the patient themselves.
- The committee commented the Participant Information Sheet is not clear to say patients will be free to leave the study at any time, and suggests using a stop sign to record this. You agreed this can be done.
- The committee commented there are three outcome measures. The committee had received the target behaviour form, but is not clear how the other two will be recorded. You informed there will be only the one record sheet. The committee also asked what if the patient becomes distressed. You had informed the committee this is tricky to record. There is the PROM and semi-structured interview at the end to see if any change occurred.
- The committee commented there should be an introduction in the Information sheets to say who you are, why you are doing this, and that this will be towards an educational qualification. You agreed to include this information.
- The committee asked as the methodology stipulates a minimum of 10 and a maximum of 20 occurrences, how can this methodology be used if you have already stated how many you will be recording. You informed the committee it will be the occurrence of target behaviour and so will record at 10 meal times and at 20 times.
- The committee commented on the use of the language used relating to benefits of this study in the Participant Information Sheet and suggest changing this to sound less of a reinforcement.
- The committee asked who Mary O'Reilly is and Dr [REDACTED]. Are they the same person? You confirmed to the committee Mary O'Reilly is your Academic Supervisor and [REDACTED] is a Consultant Psychiatrist.

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

#### **Further information or clarification required**

- The committee require the following changes to the Participant Information Sheet:
  - PALs (or is equivalent) to be added.
  - Explanation as to what will be written down for Patients PIS
  - Include information as to what will happen if a participant becomes distressed.
  - Correct all typographical errors
  - For the Carer Information Sheet, include the information the same as the IRAS form as this reads clearer.
  - An introduction as to who you are and that this study is towards and educational qualification
  - Consistency is needed throughout as to who will be doing what. Either "Nicol will" or "We will"
  - A clear explanation is needed to say what will happen if carers withdraw from the study, but the patients does not want to. What will happen to them?
- Question two of the semi-structured interview change this question to "Were there changes to their behaviour?"
- The Consent Form for Carers, include a point to say "I agree to take part in this study"

**If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact the REC Manager, Rebecca Morledge, [NRESCCommittee.EastMidlands-Northampton@nhs.net](mailto:NRESCCommittee.EastMidlands-Northampton@nhs.net)**

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 21 February 2014.

#### **Membership of the Committee**

The members of the Committee who were present at the meeting are listed on the attached sheet.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.



Yours sincerely,



**Mr Ken Willis**  
**Chair**

Email: NRESCommittee.EastMidlands-Northampton@nhs.net

*Enclosures: List of names and professions of members who were present at the meeting  
and those who submitted written comments.*

Copy to:





**University of  
Leicester**

**School of Psychology**  
**Doctorate in clinical Psychology**  
104 Regent Road  
LEICESTER LE1 7LT  
UK

Tel +44 (0)116 223 1639

Fax +44 (0)116 223 1650

Northampton Research Ethics Committee  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

24<sup>th</sup> January 2014

Dear Mr Willis,

**RE: REC Application 14/EM/0010**

Thank you for considering my application at the NRES Committee on 16<sup>th</sup> January 2014. Following our discussions and your recommendations I have made amendments.

The Participant information sheet and consent form (all one document) has been amended to include information about the project being part of an educational qualification. It also explains that the carer must take part and that if the carer withdraws, then they are also withdrawn. I have also included information about who they can talk to if they feel distressed/upset. This includes their keyworker (whose name will be inserted), one of the inclusion criteria is that the participant has a professional from the Learning Disability Service involved in their care and they will be involved to help support the participant and carer if they become distressed.

Please find enclosed the amended documents, all changes have been highlighted:

- Amended Participant information sheet and consent form (all one document, Version 1.3).
- Amended Carers information sheet (Version 1.2)
- Amended consent form for carers (Version 1.2)
- Amended semi-structured interview schedule (Version 1.2)

Please do not hesitate to contact me if further information is required. I look forward to hearing from you.

Yours Sincerely

Nicol Aphalé  
Trainee Clinical Psychologist

# Health Research Authority

## NRES Committee East Midlands - Northampton

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 883 8440

30 January 2014

Miss Nicol Aphale

University of Leicester - Clinical Psychology Department  
104 Regent Road  
Leicester  
LE1 7LT

Dear Miss Aphale,

<b>Study Title:</b>	<b>Social Stories™ as an individually tailored intervention for adults with Autistic Spectrum Disorders (ASD) and Learning Disabilities (LD).</b>
<b>REC reference number:</b>	<b>14/EM/0010</b>
<b>Protocol number:</b>	<b>R&amp;D Ref: LDIS0660</b>

Thank you for your letter of 24 January 2014, responding to the Committee's request for further information on the above research, and enclosing the following revised documents:

Document	Version	Date
Interview Schedules/Topic Guides	Semi-structured interview schedule, V1.2	24 January 2014
Participant Consent Form	1.3	24 January 2014
Participant Consent Form: Carers	1.2	24 January 2014
Participant Information Sheet	1.3	24 January 2014
Participant Information Sheet: Carers	1.2	24 November 2013
Response to Request for Further Information		24 January 2014

The further information and revised documentation has been considered on behalf of the Committee by the Chair.

The Committee would be grateful for a more complete response on the following points:

- The committee noted there are not any 'confidentiality' and 'reviewed' by paragraphs in the carer Participant Information Sheet. PALs has been included but it is not in a complaints section. All sections as in the NRES format must be included.

Any further revised document submitted should be given a revised version number and date.

The 60 day clock for issue of a final ethical opinion on this application will re-start when the Committee has received a response on the outstanding points.

14/EM/0010

Please quote this number on all correspondence

Yours sincerely,



**Rebecca Morledge**  
**REC Manager**

Email: [NRESCommittee.EastMidlands-EastMidlands@nhs.net](mailto:NRESCommittee.EastMidlands-EastMidlands@nhs.net)

Copy to: [Redacted]

Northampton Research Ethics Committee  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

4<sup>th</sup> February 2014

Dear Mr Willis,

**RE: REC Application 14/EM/0010**

Thank you for considering my application at the NRES Committee on 16<sup>th</sup> January 2014. Following your recent request to amend the Participant Information Sheet for Carers, please find attached the amended version 1.3.

Your letter stated that all sections of the NRES Guidance should be included. I felt that many of the sections listed in the guidance are not relevant to the carer, as they are not the recipient of the intervention being researched. Below is a list of the sections and an explanation of what is included and where, and what has not been included and why. The items in bold indicate where changes that have been made.

- 6.1.1 – Heading of 'Information Sheet for Carers'
- 6.1.2 – Included as 'Title of Research'
- 6.1.3 – Invitation paragraph included in bold and in a box at the beginning of the information sheet.
- 6.1.4 – Included under the question 'What is this project about?'
- **6.1.5 – A new section has been added with the question 'Why have I been invited to participate?'**
- **6.1.6 – Participation being voluntary has been included in the new section 'Why have I been invited to participate?' This is also included under the section 'What if I do not want to be involved?', which has been moved further forward in the information sheet.**
- 6.1.7 – This has not been included as the carer is not the participant. All details about what they are required to do is on the information sheet under 'What will I have to do?'
- 6.1.8 – This is not relevant to this research as there are no expenses or payments.
- 6.1.9 – Included under 'What will I have to do?'
- 6.1.10 – This has not been included as this intervention is already in use in the service and therefore the participant would receive this as the intervention.

- **6.1.11 - This has been added under 'What are the disadvantages of being involved?'**.
- 6.1.12 – This is not relevant to this research.
- 6.1.13 – This is not relevant to this research.
- 6.1.14 – This is not relevant to this research.
- **6.1.15 – This has been added under the section 'What are the benefits of being involved?'**.
- **6.1.16 – This has been added under 'What will happen at the end of the study?'**.
- **6.1.17 – This has been added under 'What if there is a problem during the study?' and includes the details of PALS.**
- 6.1.18 – Details about confidentiality are contained in the section headed "What will be done with the information collected?". There is no mention of correspondence with the GP in this section as no information about the carer will be shared with the GP. Information about the participant will be shared with the GP, which is detailed in the patient information and consent sheet.
- 6.2.1 – This is not relevant as the carer is not the recipient of the intervention.
- 6.2.2 – This is under the heading 'What if I change my mind about being involved?'.
- **6.2.3 - This has been added under 'What if there is a problem during the study?' and includes the details of PALS.**
- 6.2.4 – Information about confidentiality is under the section "What will be done with the information collected?".
- 6.2.5 – This is not relevant as the carer is not the recipient of the intervention.
- 6.2.6 – How data will be handled is explained in the section "What will be done with the information collected?".
- 6.2.7 – This is not relevant to this research.
- 6.2.8 – This is explained in the section "What will be done with the information collected?".
- 6.2.9 – The research is part of an academic qualification which is mentioned at the start of the information sheet (under the invitation box) and in the section "What will be done with the information collected?".
- **6.2.10 – This has been added under 'Who has reviewed this study?'.**
- 6.2.11 – Names of the researchers are at the top of the information sheet and contact telephone numbers are part of the headed paper.

You noted that there was no confidentiality paragraph, all information about confidentiality is under the "What will be done with the information collected?" section. You also noted that there was no reviewed by section, this has now been added (as detailed above).

Please do not hesitate to contact me if further information is required. I look forward to hearing from you.

Yours Sincerely

Nicol Aphalé  
Trainee Clinical Psychologist

05 February 2014

Miss Nicol Aphale  
Trainee Clinical Psychologist

University of Leicester - Clinical Psychology Department  
104 Regent Road  
Leicester  
LE1 7LT

Dear Miss Aphale

<b>Study title:</b>	<b>Social Stories™ as an individually tailored intervention for adults with Autistic Spectrum Disorders (ASD) and Learning Disabilities (LD).</b>
<b>REC reference:</b>	<b>14/EM/0010</b>
<b>Protocol number:</b>	<b>R&amp;D Ref: LDIS0660</b>
<b>IRAS project ID:</b>	<b>144727</b>

Thank you for your letter of 04 February 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Rebecca Morledge, [NRESCommittee.EastMidlands-Northampton@nhs.net](mailto:NRESCommittee.EastMidlands-Northampton@nhs.net).

## Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

## Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Advertisement	Social Stories poster, V1.1	29 November 2013
Advertisement	Social Stories extended poster, V1.1	29 November 2013
Covering Letter		04 December 2013



Interview Schedules/Topic Guides	Semi-structured interview schedule, V1.2	24 January 2014
Investigator CV	N Aghale	29 November 2013
Investigator CV	Mary OR	29 November 2013
Letter of invitation to participant	Social Stories referral letter, V1.1	22 November 2013
Letter of invitation to participant	Social Stories participation letter, V1.1	29 November 2013
Other: User reported outcome measure (PROM)	1.1	29 November 2013
Other: Functional Assessment Observation Form	1.1	13 December 2013
Other: Behaviour Recording Form Template	1.1	13 December 2013
Participant Consent Form	1.3	24 January 2014
Participant Consent Form: Carers	1.2	24 January 2014
Participant Information Sheet	1.3	24 January 2014
Participant Information Sheet: Carers	1.3	04 February 2014
Protocol	1.1	11 November 2013
REC application	144727/535987/1/818	04 December 2013
Referees or other scientific critique report	Research Panel Meeting minutes	11 June 2013
Referees or other scientific critique report	Interview Peer Review Form	10 October 2013
Response to Request for Further Information		24 January 2014
Response to Request for Further Information		04 February 2014

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

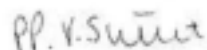
14/EM/0010

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



**Mr Ken Willis**  
**Chair**

Email: NRESCommittee.EastMidlands-Northampton@nhs.net

Enclosures: "After ethical review – guidance for  
researchers"

Copy to:



## Appendix U: Sarah's Social Story

When the Social Story™ was printed for Sarah, each page was A4 (total of four pages).

### **When Mum makes dinner**

Most evenings Mum makes dinner in the kitchen. Making dinner means doing lots of jobs. People usually need to concentrate when they make dinner. Concentration is focusing on one thing. Mum needs to concentrate when she is making dinner. When she doesn't concentrate she might drop things, burn food or burn herself.



Sometimes Mum asks me to help her make dinner. She will give me a job to do, like buttering the toast.



When I have finished my job, Mum says "thank you, you can go back to the living room". This means she doesn't need my help anymore. I can go and do something else in the living room.

When Mum is concentrating on cooking dinner, it is difficult for her to talk to people. When someone talks to Mum while she is cooking, she often says "we can talk after dinner". This means that Mum is busy and concentrating on what she is doing. She will talk to them when she has finished making dinner.



Sometimes I will have to wait to talk to Mum if she is concentrating on making dinner. This is okay! I will try to stay calm and do something else.

I can draw in my book, play on my tablet or watch TV. Mum will be really pleased if I let her concentrate on making dinner.



### Appendix V: Chronology of Research Process

<b>Date</b>	<b>Action</b>
January 2013	<ul style="list-style-type: none"><li>• Two research topics selected.</li><li>• Research supervisor allocated.</li></ul>
February 2013	<ul style="list-style-type: none"><li>• Began liaising with field supervisor.</li><li>• Undertaking critical literature review.</li></ul>
March 2013	<ul style="list-style-type: none"><li>• Critical Literature Review Submitted.</li><li>• Beginning to develop research proposal, informed by critical literature review.</li><li>• Attended NHS Trust Social Stories Group (MDT interested in the research and developing this intervention within the service).</li></ul>
April 2013	<ul style="list-style-type: none"><li>• First and second draft of Research Proposal completed.</li></ul>
May 2013	<ul style="list-style-type: none"><li>• Research Proposal submitted for academic panel review.</li></ul>
June 2013	<ul style="list-style-type: none"><li>• Academic Panel review.</li></ul>
July – October 2013	<ul style="list-style-type: none"><li>• Amending Research Proposal following panel feedback.</li><li>• Service User Lay summary submitted to Service User Reference Group and positive feedback received.</li></ul>
November 2013	<ul style="list-style-type: none"><li>• Work with Speech and Language Therapists and Service User Group to review and develop participant information and consent form.</li></ul>
December 2013	<ul style="list-style-type: none"><li>• NRES application for ethical approval submitted and NRES panel meeting booked. R&amp;D application submitted.</li></ul>
January – February 2014	<ul style="list-style-type: none"><li>• NRES Panel meeting.</li><li>• Amendments made to documents and NRES approval granted.</li><li>• R&amp;D approval granted.</li></ul>
March 2014	<ul style="list-style-type: none"><li>• Participant recruitment commenced.</li><li>• Researcher attended several MDT team meetings to advertise and promote the research and answer queries about referring individuals to the project.</li></ul>
April – July 2014	<ul style="list-style-type: none"><li>• Ongoing recruitment, with emails sent out periodically to advertise the project and psychologists mentioning it in team meetings.</li><li>• Liaising with staff regarding referrals that did not meet the project criteria.</li><li>• Met with one participant who did not consent to be involved in the project.</li><li>• Selected topic area for Literature Review and began researching undertaking a meta-ethnography.</li></ul>
August 2014	<ul style="list-style-type: none"><li>• Attended Social Stories Group – raised challenges in recruiting participants.</li><li>• Participant one Recruited and began set-up phase.</li></ul>

	<ul style="list-style-type: none"> <li>• Conducted Literature Review search and began process of quality appraisal.</li> </ul>
September 2014	<ul style="list-style-type: none"> <li>• Applied and was granted R&amp;D approval for a nearby NHS Trust as a back-up if no further participants were recruited.</li> <li>• On-going liaison with carers of Participant one.</li> <li>• Participant two recruited.</li> <li>• Attended Social Stories Group.</li> <li>• Conducting and writing up meta-ethnography for literature review.</li> </ul>
October 2014	<ul style="list-style-type: none"> <li>• Ongoing liaison with carers of Participant one and two.</li> <li>• Participant three recruited.</li> <li>• First draft of Literature Review submitted to supervisor.</li> </ul>
November 2014	<ul style="list-style-type: none"> <li>• Participant one removed from project.</li> <li>• Ongoing liaison with Participant two and three.</li> <li>• Amending Literature Review.</li> <li>• Change in field supervisor.</li> </ul>
December 2014	<ul style="list-style-type: none"> <li>• Ongoing liaison with Participant two and three.</li> <li>• Submitted revised draft of Literature Review.</li> <li>• Beginning Research Report write-up.</li> </ul>
January 2015	<ul style="list-style-type: none"> <li>• Ongoing liaison with Participant three.</li> <li>• Participant two completed the project and qualitative interviews conducted.</li> <li>• Recruitment closed.</li> <li>• Final draft of Literature Review completed.</li> <li>• Ongoing write-up of Introduction and Method.</li> </ul>
February 2015	<ul style="list-style-type: none"> <li>• Participant three removed from the study.</li> <li>• Qualitative analysis of participant two's interview and carer interview.</li> <li>• First draft of Introduction and Method submitted to supervisor.</li> <li>• Attended Social Stories group to feedback that recruitment was closed and that the results would be ready to be feedback in the next few months.</li> </ul>
March 2015	<ul style="list-style-type: none"> <li>• Reviewed results with field supervisor and first draft of Results section submitted to supervisors.</li> <li>• Introduction and Method sections amended.</li> <li>• First draft of Discussion and Critical Appraisal submitted to supervisor.</li> <li>• Completion of study from returned to NRES.</li> </ul>
April 2015	<ul style="list-style-type: none"> <li>• Final draft of whole thesis submitted to supervisor.</li> <li>• Thesis submitted to University.</li> </ul>

## Appendix W: Guidelines to authors for target journal

Below is the Manuscript Submission Guidelines for 'Autism: the International Journal of Research and Practice' as taken from the SAGE journals website (<http://www.uk.sagepub.com/msg/aut.htm>). This is the target journal for the literature review and research paper.

1. [Editorial Policies](#)
  - 1.1 [Peer review policy](#)
  - 1.2 [Authorship](#)
  - 1.3 [Acknowledgments](#)
    - 1.3.1 [Funding acknowledgement](#)
2. [Publishing Policies](#)
  - 2.1 [Publication Ethics](#)
  - 2.2 [Contributor's publishing agreement](#)
  - 2.3 [Open Access and author archiving](#)
3. [Article types](#)
4. [How to submit your manuscript](#)
5. [Declaration of conflicting interests policy](#)
6. [Other conventions](#)
  - 6.1 [Research ethics](#)
  - 6.2 [Patient consent](#)
  - 6.3 [Statistical analyses](#)
  - 6.4 [Randomized controlled trials](#)
  - 6.5 [Prisma](#)
  - 6.6 [Consort](#)
7. [Permissions](#)
8. [Manuscript style](#)
  - 8.1 [File types](#)
  - 8.2 [Journal style](#)
  - 8.3 [Reference style](#)
  - 8.4 [Manuscript preparation](#)
    - 8.4.1 [Keywords and abstracts: Helping readers find your article online](#)
    - 8.4.2 [Corresponding author contact details](#)
    - 8.4.3 [Guidelines for submitting artwork, figures and other graphics](#)
    - 8.4.4 [Guidelines for submitting supplemental files](#)
    - 8.4.5 [English language editing services](#)
9. [After acceptance](#)
  - 9.1 [Lay Abstracts](#)
  - 9.2 [Proofs](#)
  - 9.3 [E-Prints and complimentary copies](#)
  - 9.4 [SAGE production](#)
  - 9.5 [OnlineFirst publication](#)
10. [Further information](#)

*Autism* provides a major international forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

## **1. Editorial policies**

### **1.1 Peer review policy**

*Autism* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

As part of the submission process you will be asked to provide the names of 1 peer who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

### **1.2 Authorship**

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

### **1.3 Acknowledgements**

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair

who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

### **1.3.1 Funding Acknowledgement**

To comply with the guidance for Research Funders, Authors and Publishers issued by the [Research Information Network](#) (RIN), *Autism* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. All research articles should have a funding acknowledgement in the form of a sentence as follows, with the funding agency written out in full, followed by the grant number in square brackets:

This work was supported by the Medical Research Council [grant number xxx].

Multiple grant numbers should be separated by comma and space. Where the research was supported by more than one agency, the different agencies should be separated by semi-colon, with “and” before the final funder. Thus:

This work was supported by the Wellcome Trust [grant numbers xxxx, yyyy]; the Natural Environment Research Council [grant number zzzz]; and the Economic and Social Research Council [grant number aaaa].

In some cases, research is not funded by a specific project grant, but rather from the block grant and other resources available to a university, college or other research institution. Where no specific funding has been provided for the research we ask that corresponding authors use the following sentence:

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity dependent on the peer review policy of this journal outlined above, you can withhold this information until final accepted manuscript.

For more information on the guidance for Research Funders, Authors and Publishers, please visit: <http://www.rin.ac.uk/funders-acknowledgement>

[Back to top](#)

## **2. Publishing policies**

### **2.1 Publication ethics**

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics’ [International Standards for Authors](#) and view the Publication Ethics page on the [SAGE Author Gateway](#).

#### **2.1.1 Plagiarism**



*Autism* and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

## **2.2 Contributor's publishing agreement**

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

## **3.3 Open Access and author archiving**

If you or your funder wish your article to be freely available online to non subscribers immediately upon publication (gold open access), you can opt for it to be included in *SAGE Choice*, subject to payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing *SAGE Choice*. To check journal eligibility and the publication fee, please visit [SAGE Choice](#). For more information on open access options and compliance at SAGE, including self author archiving deposits (green open access) visit [SAGE Publishing Policies](#) on our Journal Author Gateway.

[Back to top](#)

## **3. Article types**

The Journal considers the following kinds of article for publication:

1. **Research Reports.** *Full papers* describing new empirical findings;

2. **Review Articles.**

(a) *general reviews that provide a synthesis of an area of autism research;*

(b) *critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.*

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, tables, text). Editors may ask authors to make certain cuts before sending the article out for review.

**3. Short Reports.** Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.

**4. Letters to the Editors.** Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

[Back to top](#)

#### **4. How to submit your manuscript**

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

*Autism* is hosted on SAGEtrack a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/autism> to login and submit your article online.

**IMPORTANT:** Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit [ScholarOne Online Help](#).

All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

[Back to top](#)

#### **5. Declaration of conflicting interests**

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. *Autism* does not require a declaration of conflicting interests but recommends you review the good practice guidelines on the [SAGE Journal Author Gateway](#).

[Back to top](#)

## 6. Other conventions

We would prefer to use the term ‘people with autism’ or ‘people with autism spectrum disorders or conditions’. We would also prefer the term ‘typically developing’ rather than ‘normal’.

### 6.1 Research ethics

All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a high ethical standard. Studies in humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of Helsinki

<http://www.wma.net/en/30publications/10policies/b3/index.html> and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee. In line with the Declaration of Helsinki 1975, revised Hong Kong 1989, we encourage authors to register their clinical trials (at <http://clinicaltrials.gov> or other suitable databases identified by the ICMJE, [http://www.icmje.org/publishing\\_10register.html](http://www.icmje.org/publishing_10register.html)). If your trial has been registered, please state this on the Title Page. When reporting experiments on animals, indicate on the Title Page which guideline/law on the care and use of laboratory animals was followed.

### 6.2 Patient consent

Authors are required to ensure the following guidelines are followed, as recommended by the International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published.

Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of patients is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic pedigrees, authors should provide assurance that alterations do not distort scientific meaning and editors should so note. When informed consent has been obtained it should be indicated in the submitted article.

### 6.3 Statistical analyses

Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are usually

required. In research papers requiring complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

#### **6.4 Randomized controlled trials**

All randomized controlled trials submitted for publication in *Autism* should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart. Please refer to the CONSORT statement website at <http://www.consort-statement.org> for more information.

#### **6.5 Prisma**

*Autism* requires a completed PRISMA checklist and flow diagram as a condition of submission when reporting the results of a systematic review. Templates for these can be found on the PRISMA website [www.prisma-statement.org](http://www.prisma-statement.org). You should ensure that, at minimum, your article reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your systematic review and may enhance its chances for eventual publication.

#### **6.6 Consort**

*Autism* requires a completed CONSORT 2010 checklist and flow diagram as a condition of submission when reporting the results a randomized trial. Templates for these can be found on the CONSORT website [[www.consort-statement.com](http://www.consort-statement.com)] which also describes several CONSORT checklist extensions for different designs and types of data beyond two group parallel trials. You should ensure that your article, at minimum, reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your trial report and may enhance its chances for eventual publication.

[Back to top](#)

### **7. Permissions**

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

[Back to top](#)

### **8. Manuscript style**

#### **8.1 File types**

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX

files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

## **8.2 Journal Style**

*Autism* conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

## **8.3 Reference Style**

*Autism* operates a Sage Harvard reference style. [Click here](#) to review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

## **8.4. Manuscript Preparation**

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

### ***8.4.1 Keywords and Abstracts: Helping readers find your article online***

The title, keywords and abstract are key to ensuring that readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#).

### ***8.4.2 Corresponding Author Contact details***

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

### ***8.4.3 Guidelines for submitting artwork, figures and other graphics***

Artwork, figures and other graphics such as tables should be uploaded through SAGE's Online Submission System alongside the main body of the text, as a separate file to ensure best quality in production. For further guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

### ***8.4.4 Guidelines for submitting supplemental files***

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

### ***8.4.5 English Language Editing***

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.

[Back to top](#)

## **9. After acceptance**

### **9.1 Lay Abstracts**

Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane ([journalautism@gmail.com](mailto:journalautism@gmail.com)). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families).

These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

### **9.2 Proofs**

We will email a PDF of the proofs to the corresponding author.

### **9.3 E-Prints**

SAGE provides authors with access to a PDF of their final article. For further information please visit <http://www.sagepub.co.uk/authors/journal/reprint.sp>.

### **9.4 SAGE Production**

At SAGE we place an extremely strong emphasis on the highest production standards possible. We attach high importance to our quality service levels in copy-editing, typesetting, printing, and online publication ( <http://online.sagepub.com/> ). We also seek to uphold excellent author relations throughout the publication process.

We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in *Autism* with SAGE.

### **9.5 OnlineFirst Publication**

*Autism* benefits from OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our [OnlineFirst Fact Sheet](#)

[Back to top](#)

## **10. Further information**

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

**Katie Maras**

Department of Psychology

University of Bath  
Claverton Down  
Bath BA2 7AY  
United Kingdom  
Email: [K.L.Maras@bath.ac.uk](mailto:K.L.Maras@bath.ac.uk)