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Family and Disability: Exploring siblings' positive perceptions and the experiences of sons and daughters of Shared Lives carers.

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate
in Clinical Psychology

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List of Abbreviations

ASD	Autism Spectrum Disorders
CBCL	Child Behavior Checklist
DBS	Disclosure and Barring Service
DOH	Department of Health
DS	Down Syndrome
IPA	Interpretive Phenomenological Analysis
LAC	Looked After Children
LD	Learning disabilities
MH	Mental health
NICE	National Institute for Health and Care Excellence
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SES	Socio-economic status
SIB	Sibling Inventory of Behavior
SL	Shared Lives
SL carers	Shared Lives carers
SL users	Shared Lives users
SMS	Smith-Magenis Syndrome
TD	Typically developing

UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Declaration

This thesis has been carried out under the supervision of Dr Jacky Knibbs and Dr Carolyn Gordon. Both supervisors supported me in the development of initial ideas and reviewed written drafts. My supervisors and a colleague were also consulted when developing codes and themes in order to validate my data analysis. Apart from these collaborations, the thesis reflects my own work. It has not been submitted for any other qualification at another university.

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Chapter 3: 2,605

TOTAL: 19,389

Summary

This thesis focuses upon the experiences and perceptions of the family and the network surrounding people with additional needs.

Chapter one presents a systematic review of the literature into the positive perceptions and experiences of children who have a sibling with a learning disability or Autism Spectrum Disorder. The findings revealed that typically developing children hold positive perceptions of their sibling relationships, and experienced positive personal growth in areas such as social competence and self-concept. The findings must be considered in the context of several methodological limitations. Nonetheless, the research highlights the benefits of acknowledging both the positive impact, as well as the challenges, of having a sibling with a learning disability or Autism Spectrum Disorder.

Chapter two is an empirical study which aims to explore the lived experiences of sons and daughters of Shared Lives carers. The model of Shared Lives provides family based care for adults with additional needs such as learning disabilities, mental health difficulties and older adults. An Interpretive Phenomenological Analysis method was used and three themes emerged from the data following participants' interviews. The limitations of the research are acknowledged and the findings are explored in relation to the implications for future research and clinical practice.

Chapter three presents a reflective account of the researcher's personal connection to the empirical study. It outlines the times that the research process has paralleled the researcher's personal experiences and explores issues surrounding the challenges and benefits of telling both the participants and the researcher's stories.

CHAPTER ONE: LITERATURE REVIEW

Exploring child siblings' positive perceptions: a systematic review of the learning disability and Autism Spectrum Disorder literature.

In preparation for submission to *Journal of Intellectual and Developmental Disability* (see Appendix J. for author's guidelines).

Chapter Word Count (excluding tables, figures, footnotes and references): 7,434

1.1 Abstract

The following literature review critically evaluates the quantitative and qualitative research into typically developing child siblings' positive experiences and perceptions of having siblings with a learning disability and/or Autism Spectrum Disorder. A systematic search of the literature that was published in the last 15 years was conducted. Sixteen articles were included in the review and assessed against a quality framework. The findings revealed that typically developing siblings reported positive attitudes towards their siblings and positive perceptions of their relationship quality. Furthermore, positive outcomes on measures of typically developing siblings' behaviour, self-concept, growth and social competence were reported. The review is restricted by the predominantly Caucasian, Western cultural focus of the studies, limiting the generalisability of the results. The results suggest that future research and clinical practice may benefit from exploring siblings' strengths and positive experience within the sibling relationships, in order to continue to support their wellbeing.

Keywords: Systematic Review, Child, Sibling, Positive Perceptions, Wellbeing, Learning Disability, Autism Spectrum Disorder.

1.2 Introduction

1.2.1 Prevalence of learning disabilities and autism: impact upon the family

It is estimated that in the United Kingdom (UK) there are approximately 1.5 million people with a learning disability (Mencap, 2013), a figure which is expected to increase 14% by 2021 (Emerson & Hatton, 2008). Similarly, prevalence rates of Autism Spectrum Disorders (ASD) for children in the UK are estimated at 1% in the population (Baron-Cohen et al, 2009). The importance of ensuring that services meet the growing need of people with ASD or a learning disability (LD¹) and their families is being recognised. A report published by the World Health Organisation (WHO) in 2012, outlines the priorities for supporting children and young people with learning disabilities and their families. One such clinical priority is for the child to be able to grow up in a family environment, recognising the value of supporting family members, including siblings, in order to facilitate this. The report concludes that future research into the experiences of siblings is crucial in order to understanding the full impact of disability upon the family.

1.2.2 Recognising the importance of siblings

Understanding the experiences of siblings of individuals with LD and ASD is a growing area of interest. Sibling relationships are one of the most enduring connections throughout the life span (Milevsky, 2013) and provide an important source of social support (Stoneman, 2001). It is thought that approximately 80% of people in the UK grow up with a sibling (Cicirelli, 1996). Siblings may play a crucial role in the support of individuals with a LD, particularly as parental carers grow older and the roles and responsibilities are increasingly transferred to brothers and sisters (Davys, Mitchell, & Haigh, 2011;

¹ Although the terms mental retardation and intellectual disability are frequently found within the literature, the present study will use the term learning disability (LD) to refer to these concepts throughout. The term autism spectrum disorders (ASD) will be used throughout to refer to a collection of pervasive developmental disabilities.

Vanhouttegham, Van Hove, D'haene, & Soye, 2013). Research into the quality of sibling relationships upon social functioning of children with a LD, concluded that those characterised by warmth and closeness were predictive of increased social functioning and fewer behavioural difficulties at school. This highlights the potential protective factors that sibling relationships may offer (Floyd, Purcell, Richardson, & Kupersmidt, 2009). The Framework for Assessment of Children in Need and their Families also recognises the impact of sibling relationships upon the welfare of children with a LD (Gray, 2000). However, the reciprocity of this positive impact upon non-disabled siblings' wellbeing is not as widely accepted.

1.2.3 Overestimating the negatives

There is an established body of research that has highlighted the impact of having a brother or sister with a LD and ASD directly upon TD (typically developing) siblings' adjustment, self-esteem, roles within the family and mental health (Davys et al, 2011; Evans, Jones, & Mansell, 2001; Giallo & Gavidia-Payne, 2006; Neely-Barnes & Graff, 2011). Connors and Stalker (2003) conclude that the dominant view of the early research in the 1970s was one of pathology, with authors assuming the position that "a handicapped child makes a handicapped family" (McCormack, 1978, p. 12).

Despite this, several reviews into the area have suggested that the negative impact of having a disabled child in the family may be minimal (Families Special Interest Research Group, 2014; Rossiter & Sharpe, 2001; Stoneman, 2005; Summers, White, & Summers, 1994). A limitation of several of the reviews is the use of broad samples. The categories of brothers' and sisters' disabilities are often not defined and both child and adult siblings' experiences are explored (Del Rosario & Keefe, 2003; Iriarte & Ibarrola-Garcia, 2010; Stoneman, 2001). Therefore it is difficult to accurately generalise the findings to child

siblings of children with a LD and ASD. Nonetheless, the above studies suggest that despite the breadth of research focused upon the negative consequences for siblings of people with disabilities, the impact of this may have been overestimated.

1.2.4 A stress and coping approach

In the 1980s there was a move towards a stress and coping model, in which families' abilities to cope and adapt to having a child with disabilities were explored (Stainton & Besser, 1998). Current literature reviews now identify several factors that are thought to influence a sibling's ability to cope, including: the behaviour of the child with a disability, the type of disability, family demands, resources, social support, parents' wellbeing, caregiving responsibilities and the parents' differential treatment of siblings (Blacher & Begum, 2011; Choi & Van Riper, 2013; Schuntermann, 2007). There is a growing body of research exploring the value of sibling support groups with the aim of enhancing siblings' coping (Evans et al, 2001; Naylor & Prescott, 2004; Puttick, 2011).

Although this shift has helped to acknowledge that siblings of children with disabilities are managing well, the child with a disability continues to be viewed as a potential stressor to the family (Dykens, 2005). Research that is focused upon the positive contributions of children with ASD or a LD within a family is much more limited, perhaps reflecting the continuing bias towards an assumption of negative outcomes.

1.2.5 Not just coping but thriving

In the last 15 years, research has recognised the need to take a balanced approach to exploring the sibling experience and has presented a range of positive and negative findings. It builds upon the notion that siblings are able to adapt and cope well with their brother or sister's disability, recognising that there may also be positive benefits from their

experiences. Reviews by Dyke, Mulroy, and Leonard, (2009) and Iriarte and Ibarrola-Garcia, (2010) outline that siblings of people with a LD show an increased tolerance of difference, maturity, compassion and a greater sensitivity towards people with disabilities. It is of course crucial to take these findings in context and to also consider the negative outcomes also outlined by the research. However, it is encouraging to find that the literature reporting on positive outcomes for siblings looks beyond the absence of negative outcomes, an idea that is mirrored in models of positive psychology.

1.2.6 Positive psychology: defining wellbeing

Positive psychology is regarded as the movement towards understanding peoples' strengths and away from the focus that is so readily placed upon pathology, disease and illness (Heffron & Bonniwell, 2011). Through exploring how people thrive, grow and develop, we can better understand how to build upon what makes them succeed. This is an approach that is also championed in therapeutic models such as narrative therapy, which aim to increase peoples' abilities to view their difficulties in the context of their existing strengths and positive experiences.

Research by Hastings and Taunt (2002) highlights the utility of focusing upon the positive perceptions of families within the disability literature. Their review of research into parents' positive perceptions of having a child with developmental disabilities identified several positive outcomes, despite parents continuing to report experiencing stress. These positive perceptions included: taking satisfaction in caring for their child, experiencing their child as a source of joy and an increase in tolerance and compassion. The review highlights that the experience of positive wellbeing and perceptions cannot merely be reduced to the absence of stress, but instead captures a person's capacity to flourish and thrive (Seligman, 2012).

1.2.7 Summary

The literature into children's experiences of having a sibling with a LD or ASD is rapidly expanding. Although several reviews have summarised the literature on both positive and negative outcomes for siblings, often they have taken a broad approach to defining disabilities. Furthermore there is a need to readdress the apparent bias within the literature which highlights the negative impact upon sibling's wellbeing or takes a stress and coping approach.

It is not the aim of this review to minimise or discount the challenges faced by siblings of children with a LD or ASD and the importance of understanding both the positive and negative aspects of siblings' experiences is recognised. However, as many of the studies outlined above highlight, children with a LD and ASD can have a positive and lasting impact upon their siblings. In line with models of both narrative therapy and positive psychology, it is not only important to acknowledge the positive aspects of TD siblings' narratives, but also to develop an understanding of what contributes to these, so that support can be tailored around these.

1.2.8 Aim of the review

The present review aims to provide the first synthesis of the recent literature into the positive perceptions and experiences of child siblings who have a brother or sister with a LD and ASD. Within the last 15 years, research has moved away from a pathological approach to siblings' experiences and so the literature from this period will be reviewed and critiqued. It is hoped that by focusing upon the positive aspects of siblings' relationships, emotions and experiences, this will help to understand what contributes to their ability to thrive and go some way into countering negative bias. Unlike previous

reviews, the present systematic review will focus primarily upon child siblings of children with a LD and ASD, excluding other disabilities.

1.3 Method

1.3.1 Search Strategy

A systematic search of the literature within three major databases (Web of Science, PsychINFO and PsychArticles) was conducted, using search terms outlined in Table 1.1. Once each search was conducted using the individual search terms, these were combined to initially search the literature published between 2000 and 2015. The final search of the databases was conducted in February 2015 therefore studies published after this time are not included. Duplicate articles were removed and studies were screened by their titles and abstracts to determine if they were primary research into the target area and if they met the inclusion and exclusion criteria as outlined in Table 1.2.

Table 1.1 Summary of search terms

Categories to define	Search terms
Population	sibling* or brother* or sister* or explode "Siblings" or explode "Sibling Relations"
Focus	explode "Positive Psychology" or positive
Impact	impact or perception* or experience* or attribution* or gain or benefit or belief or affect
Disability type	"learning difficult*" or "learning disabilit*" or "intellectual difficult*" or "intellectual disabilit*" or "mental retard*" or "developmental delay" or autism or explode "Autism" or explode "Intellectual Development Disorder"

* Indicates a truncated term.

The term “explode” indicates that where this option was available, the thesaurus and explode option was used in order to broaden the search results.

1.3.2 Inclusion and exclusion criteria

The search inclusion and exclusion criteria are outlined in Table 1.2.

Table 1.2 Summary of inclusion and exclusion criteria

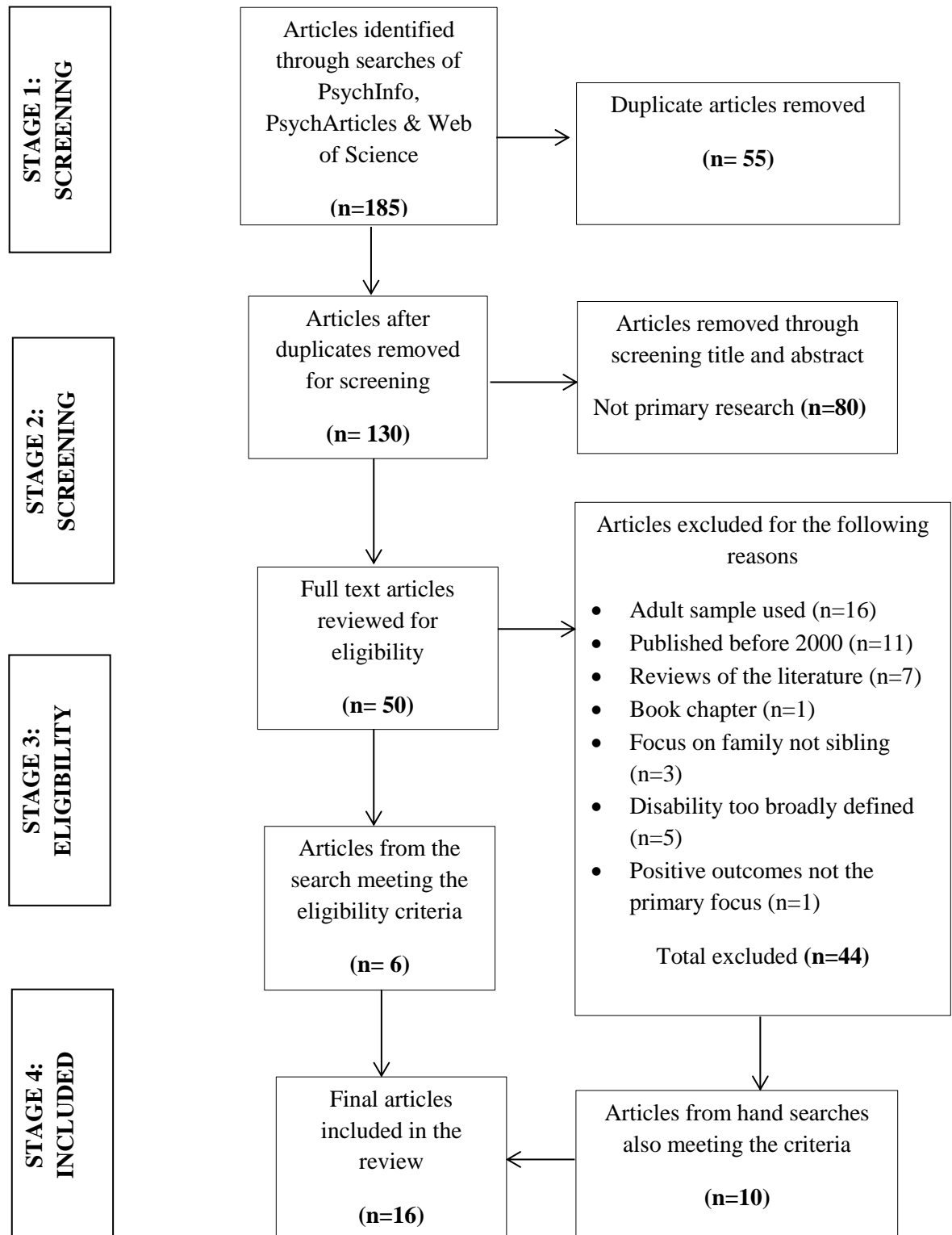
Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">Articles published in peer reviewed journals.Articles published between 2000-2015.Articles that focus on the positive impact, outcomes and experience of child siblings up to and including 19 years old.Articles that define disability as a learning disability, mental retardation, intellectual disability, developmental delay or Autism Spectrum DisordersAs this review is thought to be the first in the area, the scope of the review will be worldwide in order to ascertain a global view of the literature.	<ul style="list-style-type: none">It is beyond the scope of this review to include the literature on siblings with physical disabilities, other neurodevelopmental disabilities or chronic health conditions.Papers will be limited to those written in the English language as this is the first language of the author.Articles that focus upon adult siblings over the age of 20 will be excluded.

1.3.3 Search results

A total of 185 articles were retrieved from the search; 55 were duplicates and were therefore removed. This left 130 articles to screen against the inclusion and exclusion criteria. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram was used when screening articles and assessing eligibility (Moher, Liberati, Tetzlaff, & Altman, 2009, see Figure 1.1). 124 articles were removed during the screening and eligibility stages leaving a total of 6 articles that met the inclusion criteria. A further 10 articles were identified through hand searching the reference lists of relevant literature from the search, leaving a total of 16 articles for review.

Figure 1.1 PRISMA Flow diagram

(Moher et al, 2009)



1.4 Results

1.4.1 Quality assessment measures

Caldwell, Henshaw and Taylor's (2005) framework for critiquing health research was selected for use in the present study as it provides a guide to evaluate both quantitative and qualitative research. As this framework does not have a rating scale associated with it, a scale was developed by assigning a score of 0 (criteria not met), 1 (criteria partially met), or 2 (criteria fully met), in order to compare quality across studies. The ratings are summarised in Table 1.3 (Appendix A, quality checklists). Elliott, Fischer, and Rennie's (1999) guidelines for the publication of qualitative research studies in psychology were drawn upon when reviewing papers with a qualitative methodology.

1.4.2 Overview and design

The key characteristics of the studies identified, including methodology, measures, analysis and results which directly related to the aim of the review are summarised in Table 1.4. Information regarding the sample is also summarised; range and means of participants and their siblings' ages are reported where this information was available. Of the 16 studies identified in the current review, eight employed a correlational, quasi-experimental or cross-sectional design and eight studies, including a longitudinal study, adopted a qualitative research framework. The key findings from all 16 studies will be summarised, critiqued and implications for clinical practice discussed.

Table 1.4 Summary of the qualitative and quantitative literature included in the review

Author & Year	Country	Sample of Siblings	Children with Disability	Study Design & Measures	Analysis	Results: Positive Perceptions or Experiences	Quality Rating *
Conway & O'Neill, (2004)	UK	Siblings (n=17) 8-19 years (M=13.58)	Siblings with complex learning needs and complex Autism Spectrum Disorder (ASD) who attend a residential school 6-19 years	Qualitative research • Sibling completed interview: • Regarding how their sibling affected their lives	Qualitative approach not specified but Thematic Analysis is implied	Themes: • Best experiences include companionship, being able to share and play together. • 65% missed their sibling being at home • Pride in their sibling • Sibling had “normalised” disability • Feeling “privileged” to be their sibling • Taken on the role as “supporter” to their parents	25/34
De Caroli & Sagone (2013)	Italy	Siblings (n=140) 13-18 years (M=15.7)	ASD (n=46) DS (n=44) LD (n=50) Range & M not specified	Cross-sectional design Sibling completed measures: • Demographics information • Sibling Attitudes toward Disability Questionnaire (SADQ) • Semantic Differential Technique	ANOVA	• TD siblings across all three groups agreed with a statement that their brother or sister is a “special and sensitive person” on the SADQ • TD siblings of people with DS rated this scale the highest & the remaining groups rated it the 2 nd highest • Siblings of people with DS & a LD had the highest agreement with the statement indicating that they felt “affection and tenderness” towards their sibling	31/34

Diener, Anderson, Wright, & Dunn, (2015)	USA	Sisters (n=7) 7-14 years (M=10.41)	Brothers with ASD (n=30) High functioning ASD (n=6) Pervasive developmental disorder not otherwise specified (PDD-NOS) (n=1)	Qualitative research <ul style="list-style-type: none"> • Parent (N=6) & sibling (N=7) completed interviews: • Semi-structured interviews regarding their sibling relationships 	Thematic Analysis	Themes: <ul style="list-style-type: none"> • Sibling as nurturer • Pride in brother's achievements • Sibling's positive engagement through shared activities • Affection, friendship & enjoyment 	32/34
Findler & vardi, (2009)	Israel	Siblings (n=101) 13-18 years (M=15.49) Control group (n=89) 13-18 years (M=15.40)	Siblings with mild to moderate a LD (n=101) Control group (n=89) Range & M not specified	Matched pairs quasi-experimental design Sibling completed measures: <ul style="list-style-type: none"> • The Stress Related Growth Scale • The Perceived Family Relationship Questionnaire • The Perceived Stress Related to the Brother or Sister factor taken from Diabetes Quality of Life Scale • Level of Differentiation of Self Scale (LDSS) • Demographic information 	<ul style="list-style-type: none"> • MANOVA • ANOVA • Pearson's correlations • Paired comparison Scheffe test • Hierarchical regression analysis 	Results: <ul style="list-style-type: none"> • Siblings had significantly higher levels of personal, social & spiritual growth compared to the control group • Self-differentiation and perceived parental preference were the main contributors to growth • Siblings perceived that their brother or sister with disabilities was preferred. This was positively associated with an increase in maturity and independence expressed in personal and social growth 	31/34

questionnaire							
Graff et al, (2012)	USA	Siblings (n=21) 12-19 years (M=16)	Siblings with DS (n=21) (M=12 years) (Range not available) All had additional health problems, mean average of 4.18 health problems	Qualitative Research: <ul style="list-style-type: none"> • Sibling completed interview: • Perceptions of living with their brother or sister • Parent completed measures: • Demographics information questionnaire • The Child with Special Needs Description 	Inductive analysis	Themes: Positive effects on sibling: <ul style="list-style-type: none"> • 21/23 sibling found growing up with their brother or sister a positive experience • Easiest aspect of living with their sibling was their personality • Increased awareness of the sibling's problems and responsibility in caring for them • 7 participants believed it had made them better people 	30/34
Hames, (2008)	UK	Siblings (n=11) 4 months-14 years old Mean not available	Siblings with DS (n=5) LD (n=5) 21 months - 16.5 years old Mean & range not available	Qualitative Research: <ul style="list-style-type: none"> • Longitudinal study following 8 (10 initially) families over 12 years • Parents interviewed every 6 months for the first 5.5 years • From 6-12 years, siblings were interviewed 	Content Analysis	Themes: <ul style="list-style-type: none"> • Early caretaking behaviours • 3 siblings felt it had made them more caring & influenced their thoughts about a caring profession 	31/34

Kaminsky & Dewey, (2001)	Canada	Siblings (n=90) 8- 18 years (M=11)	Siblings with DS (n=30) ASD (n=30) Comparison group with no disability (n=30) Range & M not specified 80% younger than their sibling	Matched pairs cross-sectional design: <ul style="list-style-type: none"> • Sibling completed measures: • Sibling Relationship Questionnaire (SRQ) • Parent completed measures: • The Gillam Autism Rating Scale • Adaptive Behaviors Questionnaire • Demographics questionnaire 	ANOVA Chi-square tests	Results: Siblings of children with DS & ASD reported greater admiration, less quarrelling & competition in their sibling relationship as compared to the control group	27/34
Macks & Reeve, (2007)	USA	Siblings (n=51) 7-17 years Control group (n=36) 7-17 years M not specified	Siblings with ASD (n=51) Control group (n=36) Range & M not specified	Matched pairs quasi-experimental design: <ul style="list-style-type: none"> • Sibling completed measures: • Children's Depression Inventory Short Form (CDI-S) • Piers-Harris Children's Self Concept Scale • Parent completed measures: • Behavior Assessment System for Children-Parent Rating Scales 	<ul style="list-style-type: none"> • MANOVA • ANOVA • Pearson's correlations 	Results: <ul style="list-style-type: none"> • Siblings of children with ASD reported more positive self-concept compared to the control group • Siblings had a more positive view of their behaviour, intelligence, scholastic performance & anxiety • There was no difference on parent completed measure between the two groups 	26/34

				(BASC-PRS) • Demographic questionnaire			
Mascha & Boucher, (2006)	UK	Siblings (n=14) 11-18 years (M=14.73)	Siblings with ASD: Moderate to low functioning ASD (n=5) High functioning (n=3) Asperger's syndrome (n=3) 7- 20 years (M= 10.58)	Qualitative Research: • Sibling completed interview: • Semi-structured interview regarding their experience of their family situation & their feelings towards their siblings with autism	Content Analysis	Themes: The best part of having a sibling with ASD: • Good nature of sibling (fun, loving, humour) • Playing & having fun together • Grown, matured & developed understanding • Engaging in joint activities (playing, watching T.V., spending time outside) • 2 reported taking a caregiving role	30/34
Moyson & Roeyers, (2012)	Belgium	Sibling (n=50) 6-14 years (M=9.2)	Sibling with a LD (n=13) Sibling with DS (n=11) Sibling with profound & multiple a LD (n=14) 3-18 years (M=10.0)	Qualitative research: • Sibling completed interviews: • 3 interviews & 2 focus groups. Questions aimed at defining siblings' quality of life (QOL) in the context of their sibling relationship	Grounded Theory	Themes: • Acceptance • Pride • Caregiving • Engaging in joint activities	33/34

Petalas, Hastings, Nash, Dowey & Reilly, (2009)	UK	Siblings (n=8) 9-12 years (M=11.19)	Brother with ASD (n=8) 8-17 years (M=11.99)	Qualitative research: <ul style="list-style-type: none"> • Sibling completed interview: • Semi-structured interviews to explore perceptions & experiences of brothers' with ASD 	Interpretive Phenomenological Analysis (IPA)	Themes: <ul style="list-style-type: none"> • Acceptance • Positive views & experiences: <ul style="list-style-type: none"> - Pride in sibling's knowledge - Fun in sharing in activities - Appreciation of sibling's honest & sincere nature 	33/34
Petalas, Hastings, Nash, Reilly & Dowey, (2012)	UK	Siblings (n=12) 14-17 years (M=15.71)	Bothers with ASD (n=12) 4-18 years (M=13.02)	Qualitative research: <ul style="list-style-type: none"> • Sibling completed interview: • Semi structured interviews into siblings perceptions of ASD & experiences of their relationships 	IPA	Themes: <ul style="list-style-type: none"> • Acceptance • Positive perceptions & experiences: <ul style="list-style-type: none"> -siblings personality and humour -pride in sibling's skills -enjoyment from joint activities 	33/34
Pollard, Barry, Freedman & Kotchick, (2013)	USA	Siblings (n=119) 11-17 years (M=13.32)	Sibling with ASD (n=81) Siblings with DS (n=38) Range & M not specified	Quasi-experimental design: <ul style="list-style-type: none"> • Sibling completed measures: • Multi-dimensional Anxiety Scale for Children (MASC) • Network of Relationships Inventory 	<ul style="list-style-type: none"> • Correlation • Hierarchical regression analysis 	Results: <ul style="list-style-type: none"> • Siblings of children with DS reported greater social support (intimacy, nurturance, affection, companionship, admiration, instrumental aid & reliable alliance) & lower levels of conflict than siblings of children with ASD 	30/34

Van Riper, 2000	USA	Siblings (N=41), 7-18 years (M=11.46)	Siblings with DS (n=41) 1-18 years (M=8.36)	Descriptive correlational design <ul style="list-style-type: none"> • Mother completed measures: • The Family Inventory of Life Events (FILE) • The Family Inventory of Resources for Management (FRIM) • The Family Problem-Solving Communication Index (FPSC) • The Family Crisis Oriented Personal Evaluation Scales (F-COPES) • Child Behavior Check List (CBCL) • Child completed measure: • The piers-Harris Children's Self-Concept Scale 	Quantitative: Correlation matrix	<ul style="list-style-type: none"> • Maternal reports generally indicate good social competence and low levels of problem behaviours in the siblings • Siblings reported above average levels of self-concept • Sibling wellbeing was significantly positively correlated with family coping, problem-solving communication and family resources 	30/34
Verté, Roeyers & Buysse, (2003)	Belgium	Siblings (n=29) 6-16 years (M=11.14)	Siblings with ASD (n=29) 9-16 years (M=11.83)	Matched pairs quasi-experimental design: <ul style="list-style-type: none"> • Sibling completed measures: • Matson Evaluation of 	<ul style="list-style-type: none"> • ANOVA • ANCOVA 	Results: <ul style="list-style-type: none"> • Siblings of children with ASD aged between 12-16 scored significantly higher than the control group on measures of verbal self-concept and 	30/34

		Control group (n=29) 6-16 years (M=11.31)	Control group (n=29) 9-16 years (M=11.76)	Social Skills with Youngsters (MESSY) <ul style="list-style-type: none">• Self-Description Questionnaire I & II• Parent completed measures:• CBCL• Demographic information		honesty-trustworthiness indices of the SDQ-I, indicating higher self-concept <ul style="list-style-type: none">• Sisters of siblings with ASD rated their social skills higher than the control group on the MESSY• Siblings rated significantly higher on measures of internalising and externalising behaviours than control group	
Rivers & Stoneman, (2003)	USA	Siblings (n=50) 7-12 years (M=9.7)	Siblings with ASD (n=50) 4-12 years (M=7.6)	Quasi-experimental design: <ul style="list-style-type: none">• Sibling completed measures:• Satisfaction with the Sibling Relationship Scale• Parent completed measures:• Sibling Inventory of Behavior (SIB)• Marital Strains subscale of the FILE (Family Inventory of Life Events & Changes)• 2 Subscales from The Family Crisis Orientated Personal Evaluated Scales (F-COPES)	<ul style="list-style-type: none">• Hierarchical regression analysis• T-test	Results: <ul style="list-style-type: none">• Siblings generally rated their relationship positively• Parent and sibling measures of relationship quality positively correlated• Siblings perceived the relationship more positively than their parents	29/34

*Quality rating based upon Caldwell et al's (2005) quality rating framework.

Key:

Quantitative Studies



Qualitative Studies



1.4.3 Findings

1.4.3.1 Findings identified across the qualitative research

Across the eight qualitative studies, six main findings emerged relating to the positive impact of having a brother or sister with ASD or LD. These findings were: Sharing in fun and activities, Affection and joy from sibling's personality, Pride and appreciation, Role in nurturing and supporting, Accepting, normalising and focusing on the positives, and Personal growth.

1.4.3.1.1 Sharing in fun and activities

All eight of the studies highlight the positive impact of siblings spending time and sharing in joint activities with their brother or sister. In Mascha and Boucher's (2006) study, half of all siblings reported spending a lot of time with their sibling who had ASD, engaging in activities such as watching television or playing together. Conway and O'Neill (2004) describe how 65% of siblings missed their brother or sister with a LD or ASD "*being there*" or "*being together*" when they attended residential school. Furthermore, 14% stated that sharing and playing games together was the best memory that they had of their sibling. Similarly, in Graff et al's (2012) study exploring TD siblings' perceptions of their siblings with Down Syndrome, they concluded that siblings benefit positively from being able to spend time and engage in activities together. Diener et al (2015) reported that siblings valued engaging in activities of shared interest with their brothers with ASD, both in everyday life and in the context of a design skills programme that their brothers had participated in.

1.4.3.1.2 Affection and joy in sibling's personality

The theme of affection and taking joy from their sibling's personality was apparent in six of the studies. Sibling's humour, sense of fun, loving, forgiving and good tempered nature was referred to as some of their positive qualities by their TD siblings (Graff et al, 2012; Petalas et al, 2009 & 2012; Mascha & Boucher 2006). Several studies revealed that TD siblings take enjoyment from simply being with their sibling due to their positive outlook. TD siblings explained that this positive outlook was a source of inspiration; (Graff et al, 2012; Petalas et al, 2012). Diener et al (2015) highlighted that siblings felt affection for their brothers who had ASD even in light of some more challenging aspects of their personalities. Moyson and Roeyers (2012) also capture the deep emotional bond between siblings, with one TD sibling emphasising her love for her sister.

1.4.3.1.3 Pride and appreciation

Sibling's pride in their brother or sister's achievements and the appreciation that they feel for them, was a common theme across five of the studies. TD siblings reported feeling "*privileged*" to have their sibling and felt pride in their ability to manage their behaviour and in their skills when playing on the computer (Conway & O'Neill, 2004; Moyson & Roeyers, 2012; Petalas et al, 2012). Diener et al (2015) outlined a theme of Pride in Accomplishment to describe sibling's delight and surprise in observing their brother's achievements whilst participating in the technology design skills programme. The researchers described how this may have been the first opportunity for many siblings to fully appreciate their brother's skills, creating a shift in their relationship dynamic.

Finally, Petalas et al (2009) described how siblings expressed great pride in their brothers' knowledge, particularly in the context of their ASD. Siblings acknowledged that everyday life can be harder for their brother and felt pride in how they are able to manage this. Furthermore, a sibling in the study noted that he appreciated his brother greatly, expressing a desire to convey this more to his brother.

1.4.3.1.4 Role in nurturing and supporting

All eight studies capture the role that siblings play in nurturing, supporting and taking care of their siblings. Hames's (2008) longitudinal study highlights that children displayed caretaking behaviours towards their siblings with learning disabilities from as early as two years of age. Although siblings felt the desire to care for their brothers or sisters, they expressed awareness that it should not be a responsibility imposed upon them.

Siblings reported engaging in care taking tasks (Graff et al, 2012; Diener et al, 2015). Sibling's satisfaction in taking on a caring role was outlined by one participant who stated that they enjoyed taking care of their sibling (Moyson & Roeyers, 2012). Furthermore, TD siblings expressed a desire to continue to support their sibling in later life (Graff et al, 2012; Petalas et al, 2012). Siblings described how these experiences had helped them to develop into caring people, learn how to care for others and influenced their thoughts on a future career in related professions (Hames, 2008; Petalas et al, 2009; Conway & O'Neill 2004).

1.4.3.1.5 Accepting, normalising and focusing on the positives

Three studies describe how TD sibling's view of disability has been normalised by their experiences with their siblings (Conway & O'Neill, 2004; Petalas et al, 2012; Petalas et al, 2009). Siblings accepted that their brother's ASD was a part of them, but continued to view their brother in the context of a typical sibling relationship (Diener et al, 2015; Petalas et al, 2009).

Moyson and Roeyers, (2012) report that TD siblings' acceptance of their sibling's learning disability helped them to focus upon the qualities which make their siblings special. TD siblings are able to focus on what their sibling can do rather than what they can not. Petalas et al (2012) also captures a sense of siblings being special because of their ASD.

1.4.3.1.6 Personal growth

Three studies reported that TD siblings experienced personal growth as a result of their experiences. Seven siblings in Graff et al's (2012) study commented that having a sibling with a LD had made them into better people. One sibling outlined that he was more patient and considerate of peoples' feelings as a result of his experiences.

TD siblings reported becoming more humble as a result of seeing the difficulties that their sibling has faced and feeling inspired by the way they managed this adversity. Furthermore, one participant commented that he had gained acceptance and responsibility. Siblings' increased maturity, independence and compassion were also highlighted in the research.

Siblings in Hames (2008) study commented that they were more independent as a result of taking on a caring role for their sibling with a LD and also due to taking care of themselves from a young age. Masha and Boucher (2006) report on how a

sibling felt that she had grown in maturity and developed her understanding as a direct result of her experiences. Finally, there was also evidence that siblings believed that they were more caring and compassionate people, due to their experiences of growing up with a disabled sibling (Hames, 2008).

1.4.3.2 Findings from the quantitative research

1.4.3.2.1 Relationship quality

Sibling's relationship quality was measured by three studies. Rivers and Stoneman (2003) assessed relationship quality between TD siblings and their brother or sister with ASD. A positive correlation between sibling and parent rated relationship quality was found; however there was a tendency for siblings to rate their relationships more positively than parents' estimates. The authors concluded that siblings were satisfied in their relationship despite parents underestimating the positive impact of this.

Pollard et al (2013) employed a cross-sectional design to compare the relationship quality of TD siblings of children with Down Syndrome (DS) or ASD. The results revealed that when controlling for extraneous variables, siblings of children with DS reported greater overall relationship quality, increased social support within their sibling relationship and decreased negative interchanges with their sibling when compared to TD siblings with ASD.

Extending this methodology, Kaminsky and Dewey (2001) also compared TD sibling relationships with their sibling with either DS or ASD, with the addition of a control group of TD siblings of non-disabled children. The authors concluded that siblings of children with DS reported significantly higher levels of closeness and intimacy in their sibling relationships, when compared to the children of siblings with no disability or ASD. Furthermore, both siblings of children with DS and ASD

reported less conflict and competition in their relationships and greater admiration and affection in their sibling relationships than children in the normally developing dyads.

1.4.3.2.2 Attitude towards siblings

De Caroli and Sagone (2013) compared TD siblings' attitudes towards their disabled sibling across three groups: those of siblings with ASD, a LD or DS. TD siblings were asked to rate their degree of agreement with positive or negative statements about their siblings. The results highlighted that siblings across all groups, had the highest or second highest level of agreement with statements indicating that their sibling was a "*special and sensitive person*" and that they felt "*affection and tenderness*" towards them.

1.4.3.2.3 Self-concept

Four studies measured sibling's self-concept. De Caroli and Sagone (2013) compared measures of self-concept across the aforementioned sibling groups. TD siblings of children with DS and a LD had significantly more positive self-concept than those with ASD siblings.

Verte et al (2003) measured the self-concept of sisters of children with high functioning autism. Those aged between 12-16 had more positive self-concept than sisters in the comparison group.

Similarly, Macks and Reeve (2006) compared self-concept in siblings of children with ASD to a control group. They combined measures of self-concept, behaviour and depression to assess TD sibling's overall psychosocial and emotional adjustment. The authors report that TD siblings scored significantly higher on measures of the total scale than the control group, indicating more positive self-

concept. The authors found that once demographic risk factors (such as low socio-economic status (SES), being older than the child with ASD and only having one sibling) were controlled for, TD siblings of children with ASD had increased psychosocial and emotional adjustment compared to the control group.

Self-concept in siblings of children with DS was measured by Van Riper (2000). The author examined the wellbeing of TD siblings of children with DS in the context of family demands, resources, problem-solving, communication and coping. Although there was no control group to draw comparisons with, siblings rated their self-concept favourably.

1.4.3.2.4 Behaviour

Several studies examined TD sibling's behaviour; however only the studies in which positive outcomes on this measure were reported will be discussed.

Macks and Reeve (2007) used the Piers-Harris to measure TD siblings' ratings of their own behaviour against a control group. The authors conclude that TD siblings of children with ASD reported significantly more positive behaviours than those in the control group. However, it should be noted that this outcome was not supported by the results of parent ratings of sibling's behaviour.

1.4.3.2.5 Sibling growth and social competence

Findler and Vardi (2009) investigated factors impacting upon sibling growth such as perceived parental treatment, self-differentiation and stress. They compared measures of personal, social and spiritual growth between siblings of children with and without LD. The results revealed a significant group difference, with TD siblings of children with a LD experiencing greater personal, social and spiritual growth. The authors concluded that siblings of children with a LD perceived their siblings to be

favoured by their parents. This perception of preference was significantly associated with increased personal growth such as greater independence and maturity.

Social competence was measured in Verte et al's study (2003). The findings reported that sisters of children with high functioning autism reported higher levels of social competence in comparison to the control group. Van Riper (2000) looked at maternal ratings of social competence using the Child Behavior Checklist (CBCL) as part of their assessment of sibling's wellbeing. Mothers generally rated siblings as having good social competence, particularly when they were from a family that reported greater family resources (e.g. extended family support).

1.4.4 Assessment of quality

An overview of the studies quality ratings can be found in Table 1.3 (Appendix A). When rated using Caldwell et al's (2005) framework, the qualitative studies ranged from 25-33 out of a possible score of 34. Scores were also summed across all eight studies for each quality criteria to obtain a score out of a possible 16. Scores ranged from 10-16. The quality rating of the quantitative studies ranged from 26-31 out of a possible total score of 34. Summed scores across all eight studies for each quality criteria ranged from 6-16.

1.4.4.1 Design

The majority of quantitative studies included in the review failed to clearly state the design utilised. This is considered a limitation as indicated by the low score obtained on the quality framework (9/16, see Appendix A). Although the design was implicit in the method, this was not explicitly stated by seven out of eight studies, the exception being Van Riper's (2000) clarification around the descriptive correlational design.

Across all the studies included in the review, only one qualitative study employed the use of a longitudinal research design. Hames' (2008) study explored TD siblings' understanding of their siblings' learning disability across a twelve year period. It highlighted that change in TD siblings' awareness of the social impact of disability led to an increase of feelings of embarrassment as TD siblings grew older. The remaining studies included in the review administered outcome measures or explored TD siblings' perceptions and experiences at only one time point, failing to capture the rich changes which may occur across siblings' life spans. This can be considered a further limitation of the research.

1.4.4.2 Control groups

The use of control groups are significant strengths of four of the eight quantitative studies (Findler & Vardi, 2001; Kaminsky & Dewey, 2001; Macks & Reeve, 2007; Verte et al, 2003). It enables outcomes of TD developing and disabled (LD & ASD) sibling dyads to be compared against a reliable baseline of non-disabled sibling dyads, across a variety of measures. The absence of a control group in De Caroli and Sagone's (2013) research is a limitation as it is not possible to compare the attitudes of children with siblings who have disabilities (ASD, a LD or DS) to those with a TD sibling. Kaminsky and Dewey (2001) rectify this with the addition of a control group, increasing the validity of their findings.

1.4.4.3 Transferability and generalisability of findings

The main limitations of the qualitative and quantitative studies included in the review, relate to the transferability and generalisability of the findings. This criterion received low scores of 10/16 and 8/16 respectively, across all studies when rated against Caldwell et al's (2005) quality framework (Appendix A).

1.4.4.3.1 Recruitment

Purposive and convenience sampling methods were employed in all 16 studies reviewed. TD siblings of children with disabilities were recruited via a variety of services, including: welfare services, special residential or day schools, parent support groups, research registries and interest groups, local charitable organisations, rehabilitation centres and pre-school services. Families who access these services may be experiencing greater difficulties and/or increased levels of support in comparison to families that do not. The recruitment of participants from these support services and specialist agencies can therefore be considered a limitation, given the impact it may have upon the transferability and generalisability of the findings.

1.4.4.3.2 Sampling

Several qualitative studies utilised male only samples of children with ASD, TD children who were all female, or older than their siblings (Diener et al, 2015; Graff et al, 2012; Masha & Boucher, 2006; Moyson & Roeyers, 2012; Petalas et al, 2009 & 2012). In light of the above, these samples may not be truly representative of the population of TD siblings and therefore the transferability of the findings is questionable. A further criticism of two qualitative studies is that they fail to define the age range or mean of the sample of siblings with ASD or a LD included in the research (Conway & O'Neill, 2004; Diener et al, 2015). It is therefore difficult to ascertain whether TD siblings' experiences are affected by their brother or sister's age, limiting the transferability of these results.

All eight quantitative studies and seven qualitative studies clearly define the disability status of TD siblings' brothers or sisters. The exception to this was Conway and O'Neill's study (2004). They explain that students attending the

residential school from which they were recruited, have “severe and complex learning needs.” 75% were described as having “very complex autism”. It is therefore difficult to gain clarity around the impact of siblings differing disabilities upon TD siblings’ experiences and can be considered a limited of the research.

1.4.4.3.3 Ethnicity and culture

Ethnicity and culture are further variables that are useful to consider when evaluating the generalisability and transferability of the findings to a wider population. Five of the eight quantitative studies are conducted in Canada or America, with two taking place in Europe. An exception to this is Findler and Vardi’s (2009) study which is conducted with a sample of Israeli participants. Five of the eight qualitative studies are conducted in the UK; two take place in the USA and one in Belgium.

Furthermore, the majority of participants included across all sixteen studies are of white American/European ethnicity. In light of this, the findings of the review may only be generalisable or transferable to western European and American populations.

1.4.4.3.4 Socio-economic status

Ten studies did not report information regarding participants SES (Conway & O’Neill, 2004; De Caroli & Sagone, 2013; Mascha & Boucher, 2006; Petalas et al, 2009 & 2012; Pollard et al, 2013; Verte et al, 2003). Although, three studies reported annual income values and education levels for participants’ families, SES was not explicitly stated (Graff et al, 2012; Kaminsky & Dewey, 2001; Moyson & Roeyers, 2012). Across five studies which reported upon SES, the majority of participants were from families of middle or upper SES (Diener et al, 2015; Findler & Vardi, 2009; Macks & Reeve, 2007; Rivers & Stoneman, 2003; Van Riper, 2000). The exception to this was Hames’ (2007) study in which participants were mostly from

families of low SES. Hodapp , Glidden, and Kaiser (2005) postulated that the majority of sibling research is conducted on European-American families from middle class backgrounds. This can also be considered a limitation of the studies outlined in the present review, limiting the transferability and generalisability of the findings.

1.4.4.4 Systematic bias

A major limitation of several of the quantitative studies is the lack of control for systematic bias, which refers to factors that can distort comparisons between groups (Greenhalgh, 2001). In De Caroli and Sagone's (2013) cross-sectional study, the authors do not report demographic information for disabled children within the sibling dyads. It is therefore unclear whether there were any confounding variables such as the disabled sibling's age or severity of disability which may have influenced comparisons between groups. Similarly, in Kaminsky and Dewey's (2001) study, there were a higher proportion of male siblings with ASD compared to those with DS or in the control group. Findler and Vardi (2009) report significant difference in religiosity and economic status between the experimental and control groups. Drawing accurate conclusions across groups in these studies is therefore compromised.

1.4.4.5 Reliability and validity

1.4.4.5.1 Internal reliability of measures

Six studies report the Cronbach's alpha coefficients ranging from satisfactory to good, of some or all of the measures used (De Caroli & Sagone, 2013; Findler & Vardi, 2001; Kaminsky & Dewey, 2001; Pollard et al, 2013; Rivers & Stoneman, 2003; Van Riper, 2000). These coefficients indicated internal reliability across the

subscales of the measures. Verte et al (2003) reported that the psychometric properties of the measures used were well established, while one study failed to include any information on the internal reliability of the measures (Macks & Reeve, 2007).

1.4.4.5.2 Construct validity

The three quantitative studies which explored the quality of siblings' relationships all employed the use of different psychometric measures (Kaminsky & Dewey, 2001; Pollard et al, 2013; Rivers & Stoneman, 2003). As a result of the different psychometrics used, it is unclear whether the measures capture the same constructs of relationship quality, making it difficult to draw valid comparisons of the results across the studies. Similarly two studies utilised different measures of children's self-concept (De Caroli & Sagone, 2013; Verte et al, 2003). There are clear differences between the underlying constructs of these measures, suggesting that comparisons between the findings cannot accurately be drawn.

1.4.4.5.3 Validity checks and credibility of qualitative data analysis

In line with the Elliot et al. (1999) good practice guidelines for conducting qualitative research, authors in the studies have clearly outlined their methodological and theoretical orientation. Conway and O'Neill (2004) are the exception, as although the use of thematic analysis is implied, the methodology of data analysis is not clearly stated. A strength of five of the studies is the inclusion of credibility and validity checks such as triangulation, consultation within the research team, cross-checking and utilising participants as co-researchers to assess validity of the data (Petalas et al, 2009, 2012; Moyson & Roeyers, 2012; Diener et al, 2015; Graff et al, 2012). The credibility of data analysis is a limitation of the remaining three studies,

as they do not make specific reference to validity measures (Conway & O'Neill, 2004; Hames, 2008, Mascha & Boucher, 2006). This is reflected in the ratings on the Caldwell et al (2005) quality framework as this criterion received the joint lowest score across all studies (see Appendix A).

1.4.4.6 Social desirability bias

A further threat to the credibility of findings across all eight qualitative studies is the possible presence of social desirability bias (Kirk & Miller, 1986). In light of the potentially sensitive topics covered across the interviews, it is possible that siblings' responses may not always accurately reflect their true experiences and are influenced by perceptions of social desirability. This potential bias should be considered when interpreting findings. A strength of Moyson and Royer's (2012) study is the particular attention the researchers paid to developing trust and openness with participants in order to minimise the effects of social desirability bias. Through conducting a series of three interviews guided by participants, the authors concluded that participants felt at ease to share their experiences, thus contributing to the quality of the research.

Three of the quantitative studies drew their findings from sibling completed measures (De Caroli & Sagone, 2013; Findler & Vardi, 2001; Pollard et al, 2013). As parent completed measures are not included alongside sibling's self-report measures in these studies, the impact of social desirability bias may also be pertinent to consider.

1.4.4.7 Consideration of ethical issues

The lack of consideration of, or failure to report ethical issues, is also a limitation of several of the studies included in the review.

This criterion was rated as 12/16 across all qualitative studies on the quality framework. Diener et al (2015) and Graff et al (2012) failed to acknowledge ethical considerations. Furthermore, ethical approval was not obtained prior to the start of the study in research by Hames (2008). The remaining studies outlined ethical considerations regarding obtaining informed consent from either parents or children and ensuring the data was anonymised (Conway & O'Neill, 2004; Mascha & Boucher, 2006). A strength of the research by Petalas et al (2009 & 2012) is that the authors obtained consent from the children with ASD to have their personal information discussed in the study. In line with debriefing procedures, the researcher asked participants for their feedback and reflections following the interview. Moyson and Roeyers (2012) similarly gave considerable thought to ethical procedures; acknowledging the emotional impact of the interview upon TD siblings and allowing for additional time at the end for participants to separate themselves from the interview.

When rated against the quality framework, the quantitative studies obtained a score of 6/16 on the ethical considerations criterion. Four studies omitted any information relating to ethics (Macks & Reeve; 2007, Rivers & Stoneman, 2003; Van Riper, 2000; Verte et al, 2003). The remaining five studies gave consideration only to issues of consent and anonymity; affording participants the right to withdraw from the study was not reported.

1.5 Discussion

The aim of this review was to critically evaluate the literature published within the last 15 years, exploring the positive experiences and perceptions of TD siblings under the age of 20. All TD siblings participating in the studies reviewed had a

biological sibling with either a LD and or ASD and so the findings are generalisable only to these populations.

1.5.1 Summary of the qualitative and quantitative findings

The 16 studies included in this review make an important contribution to the research base into child siblings' perceptions and experiences of having a brother or sister with ASD or a LD. TD siblings with both brothers and sisters with a LD and ASD reported a number of positive experiences and perceptions, including: sharing in fun and activities with their sibling, affection and joy from their sibling's personality and pride and appreciation of their sibling. In addition, TD siblings reported taking on a role in nurturing and supporting their sibling, accepting and normalising disability, focusing on the positive experiences and finally experiencing personal growth. Similarly the quantitative studies highlighted that TD siblings reported positive attitudes towards their siblings and positive perceptions of their relationship quality. Furthermore, positive outcomes on measures of TD sibling's behaviour, self-concept, growth and social competence were reported.

The findings from the review can be further understood in the context of positive psychology models of psychological wellbeing. Ryff and Keyes (1995) outline the following six factor model to capture constructs which are thought to contribute to psychological wellbeing: personal growth, self-acceptance, purpose in life, autonomy, positive relationships and environmental mastery. The overlap between some of the constructs in the model and the findings from the present review, add weight to the notion that TD siblings of people with a LD and ASD are thriving in many ways.

It is important to hold in mind the limitations of the studies included in the review when considering the findings. Across the studies there was great variation of the

severity of siblings' learning disability or ASD, a variable that may impact upon TD siblings' experiences and lead to a lack of homogeneity within the samples. Several studies failed to control for systematic bias when drawing comparison between groups. The possible presence of social desirability bias in both the quantitative and qualitative research, presents a further threat to the credibility of the findings. Siblings may have been more likely to complete self-report measures and discuss their experience from a socially acceptable standpoint. An absence of validity measures in the data analysis is a limitation of three studies in the qualitative literature (Conway & O'Neill, 2004; Hames, 2008, Mascha & Boucher, 2006). Furthermore, it is difficult to draw conclusions from the findings across the quantitative literature, due to the lack of information regarding the construct validity of the psychometric measures employed.

1.5.2 Limitations of the review

The current review explores the positive perceptions and experiences of TD siblings with brothers and sisters who have a LD (including Down Syndrome and Smith-Magenis syndrome) and ASD. Siblings of children with ASD may experience different challenges and rewards compared to siblings of children with other disabilities, suggesting that their experiences may not be comparable (Morgan, 1988). Taking this broad approach to exploring the positive perceptions of TD siblings could be considered a limitation of the present review.

Although a worldwide search of the literature was conducted, the present review is inherently biased by the exclusion of studies written in languages other than English. Despite the inclusion of small Israeli, Hispanic, African American and multiracial populations, the remainder of the studies are conducted with samples of predominantly white, middle class participants from Europe and America.

The experiences of TD siblings in cultures other than those represented in the review may differ significantly given the diversity in health and social care provision across cultures. The majority of the studies have recruited participants via health and social care services and support groups. It is likely the TD siblings represented in the present review are able to access good quality health and social care, a variable that may impact upon their ability to draw positives from their sibling relationships. Furthermore, it is important to consider the impact of cultural variations in attitudes towards disability and family roles or expectations. Whyte and Ingstad (1995) argue that disability is culturally constructed, suggesting that it is only in the most Southern countries that this concept exists. This lack of exploration of cultural difference is a further limitation of the review and the findings should be considered within this context.

1.5.3 Implications for future research

The findings here have implications for future research into the area. Firstly it indicates that TD child siblings of people with ASD and a LD report positive perceptions of their sibling relationships, experience personal growth, positive self-concept, increased social competence and engage in nurturing behaviours. Future research would therefore benefit from acknowledging siblings' strengths and positive perceptions, capturing this aspect of their experiences, rather than exclusively focusing upon the presence or absence of difficulties. The development of specific measures aimed at capturing wellbeing and positive perceptions in the context of families with disabled children, would support this.

TD sibling's perception of their brother or sister's disability changes over time (Hames, 2008). Therefore their positive perceptions and experiences are also likely to shift across the lifespan. It would be useful for research in this area to explore TD

siblings' positive perceptions and experiences in adulthood, particularly given the increased responsibilities that are often placed upon them at this time (Heller & Arnold, 2010).

Research by Hastings, Allen, McDermott, and Still (2002) concluded that mothers' positive perceptions of their children with ASD were positively associated with their ability to reframe the situation, through acknowledging the families strengths and abilities to manage well. The authors concluded that positive perceptions of having a child with disabilities in the family may enhance family coping. It may therefore be useful for future research to further investigate the potential link between TD siblings' positive perceptions and their increased psychological wellbeing.

1.5.4 Clinical implications

The findings highlight the benefits many TD siblings report in terms of their positive sibling relationships and personal growth. These strengths within the relationship and the person may be helpful to draw upon when considering supporting TD siblings within clinical practice. A strengths based approach is at the centre of several therapeutic models including positive psychology, solution focused and narrative therapy. Narrative therapy advocates helping people to move away from becoming saturated in their difficulties and towards creating a more complete 'narrative' of their experiences which also recognises the positives. In light of the findings from the review, approaches such as narrative therapy may have a particular value in enabling TD siblings to continue to draw upon their strengths and thrive in spite of any difficulties that their sibling relationships may bring about for them. The utility of sibling support groups in offering TD siblings the opportunity to engage in time away from their brother or sister and to express their difficult feelings about their sibling relationships, have been evidenced (Puttick, 2011; Naylor &

Prescott, 2004). The results of the present study suggest that there may also be some benefit in supporting TD sibling and their brother or sisters to build upon the strengths within their sibling relationships. This is perhaps best demonstrated in Diener et al's (2015) research. TD siblings' positive perceptions regarding their brothers with ASD increased following their joint participation in a family-focused technology programme. This suggests that TD siblings may also benefit from supportive interventions which promote and nurture the sibling relationship, such as those drawing upon models of positive psychology or narrative therapy.

1.5.5 Conclusion

The present review provides the first summary of the literature that focuses on child siblings' positive perceptions and experiences of having a sibling with ASD and or LD. The results highlight that TD siblings hold positive perceptions regarding their sibling relationships and experience a number of positive outcomes including personal growth, good self-concept and engaging in pro-social behaviours. Although these positive findings must be taken within the context of the challenges also reported by TD siblings, the findings go some way to redress the bias within the literature that has long been focused upon the negative implications of having a sibling with ASD or LD. The findings support the recommendation for future research to continue to explore the link between TD siblings' positive perceptions of their sibling relationships and the potential protective effect this may have upon their wellbeing.

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CHAPTER TWO: EMPIRICAL PAPER

Part of the family: A qualitative enquiry into the experiences of sons and daughters of carers, offering family based care to adults under the Shared Lives scheme.

In preparation for submission to *Health & Social Care in the Community*. Further amendments to the references will be made in accordance with the author's guidelines (see Appendix K). These have been delayed in order to preserve consistency throughout the thesis.

Chapter Word Count (excluding tables, figures, footnotes and references): 9,350

2.1 Abstract

Shared Lives is a widely used model of family based care for adults over the age of 16, who need additional support to live independent lives. Despite the scheme acknowledging the importance of the supportive role of the carer's wider family, there is no research to date which explores these experiences. In light of the absence of research within this population, the present study uses an Interpretive Phenomenological Analysis approach to explore the lived experiences of sons and daughters of Shared Lives carers. The analysis of semi-structured interviews with eight participants, revealed three superordinate themes: Start of a new chapter, Part of the family: building relationships, and Ambivalence. The findings from this explorative study can be used to drive forward future research into the area. Clinical implications for the findings focus upon informing policy and guidance within Shared Lives and shaping support services for families that provide care.

Keywords: Shared Lives, family based care, Adult placement Scheme, sons and daughters

2.2 Introduction

2.2.1 Defining Shared Lives

Shared Lives (SL) is a scheme which provides family based care to adults with a variety of different needs, including individuals with learning disabilities (LD), mental health (MH) difficulties, physical disabilities, dementia, care leavers, disabled children becoming young adults, parents with a LD and their children, people who misuse substances and ex-offenders (Shared Lives Plus, 2014).

The scheme is a widely used model of care in the United Kingdom (UK), with the latest scoping report revealing that there are 121 schemes in England alone, supporting approximately 9,660 people (Shared Lives Plus, 2014). Although younger (16-18) and older adults (≥ 65) can be supported by this model of care, the majority of Shared Lives users (SL users²) are of working age (81%). The largest proportion of SL users have a LD (80%), whilst SL users who have MH difficulties and dementia make up 8% and 3% of this population respectively.

2.2.2 How people are supported

The scheme offers services such as respite care, support towards independent living, day support arrangements and outreach work to support people in their own homes. However, 50% of the support offered by the scheme is long term residential care arrangements, in which up to three SL users live together in their carer's family home. In this way, SL users become part of the carer's family, surrounding community and social networks (Brookes & Callaghan, 2013). A recent survey revealed that SL carers often support only two or three SL users over several years

² Shared Lives users (SL users) is the term used to refer to adults receiving care and support under the Shared Lives scheme as defined by Shared Lives plus (2014). As such, this term has been adopted throughout the paper.

(Shared Lives Plus, 2014). The survey found that SL carers provided support including respite care, day care and long term residential placements, to an average of six SL users across a five year period. This highlights the long-term nature of the care arrangements and stability of relationships that form.

2.2.3 History of family placement

The development of SL, previously known as the Adult Placement Scheme, is rooted in a long history of family based models of care. Fiedler (2005) cites the Liverpool Personal Service Society as one of the longest running services which has seen carers opening up their homes to support people for 30 years.

Research into the efficacy of family placement schemes initially began to emerge during the 1980s, with the development of Durham County Council's Family Placement Scheme for adults with a LD (Dagnan & Drewett, 1988). It was viewed as a favourable alternative to residential care homes, which at the time were believed to provide "little individual autonomy" (p. 544). The model fitted well with the drive towards more community based care services at the time, which emphasised the importance of normalisation, integration and home life over institutional care (Dagnan & Drewett, 1988).

Towards the end of the 1980s, more than half of all local authorities had commissioned a family placement service for adults with a LD (Dagnan, Nagel, Thompson, & Drewett, 1990). The Adult Placement Scheme was one such service delivering this type of care, which emphasised the importance of their experience "living with a caring family in ordinary housing" (Jones, 1989, p. 246).

2.2.4 A family ethos

The core value of a shared family experience, continues as the ethos of the SL scheme today, which emphasises, “The goal is ordinary family life” (Shared Lives Plus, 2013a, p. 6). Unlike in more traditional residential care home settings, carers are more likely to view placements as a process of taking someone into their family and social network (Dagnan, 1997). SL users often participate in family events such as weddings and develop lasting relationships with the family (Shared Lives Plus, 2013a).

The limited research base into carer and service user experiences highlights the strong family bonds that can develop through placements. Dagnan and Drewett (1988) interviewed 13 adults with a LD and 10 carers about their experiences of the placement and their relationships with one another. Both adults using SL and their carers used terms such as a “member of the family” and “friend” whilst describing their relationships. Furthermore, all SL users explained that their “best friend” was someone living within the household and one SL user referred to his carer as his “mam.”

Similarly, McConkey, McConaghie, Roberts and King (2005) conducted semi-structured interview of 30 SL carers³ of people with LD. They found that carers valued their company and gained a sense of achievement through supporting people. One carer explained; “You become so very attached to them, they become part of the family” (p.135).

2.2.5 The role and responsibility of the family

SL carers are self-employed and are not permitted to employ staff to help with supporting people in the home (Brookes & Callaghan, 2013). Despite this, the

³ The term SL carer will be used to refer to Shared Lives carers.

demands placed upon carers may be great, emphasising the potential need for additional support. “There is no clocking in or clocking off” (Shared Lives Plus, 2013a, p.6) and as in many families where a member has additional needs, the wider family members can play an important role in supporting individuals.

Research by Dagnan, (1994) further supports this, suggesting that family members of the SL carer are often called upon to provide relief. Furthermore, Dagnan and Drewett (1988) suggest “There is the possibility of subtle pressure being brought to bear on other members of the carer's family to continue to care for the client when the present carer is no longer able to.” (p. 572). Indeed the family’s supportive role is inherent within the scheme: “The character of the supportive relationships within SL is based on that of the supportive relationships within families and extended families” (Shared Lives Plus, 2013b, p.10). Despite this, the limited research into SL has been entirely focused upon the experiences of SL carers, SL users or SL staff members; rendering the experiences of the wider family unknown (Brookes & Callaghan, 2013; Dagnan & Drewett, 1988; McConkey et al, 2005).

2.2.6 Children of Shared Lives carers

A recent review of demographic information revealed that 80% of SL carers are over 50 (Shared Lives Plus, 2014). Gage reports that a typical SL carer is “a middle-aged woman with grown up children” (1995, p. 644). Furthermore, in a review of 35 SL carers, 83% had between one and six children, with some having grown up and left home (McConkey et al, 2005). Despite the high likelihood of SL carer’s children being part of the supportive network around the SL user, their experiences have not been considered in any existing research. SL presents a brief case study of Mary, a SL carer, highlighting the active role that her children play; “It wasn’t only Mary that got involved; the rest of the family did too! Her children remember vividly those

who stayed with them. To them the experience added to what being a family meant.” (Shared Lives Plus, 2014, p.11). This brings to light the potentially hidden members of a family who are also part of, and contribute to, this unique experience. This issue of hidden family members is paralleled in the literature on foster care.

2.2.7 The literature on foster care

2.2.7.1 A model of adult foster care

The term “foster care” is not used by SL, however the notion that this model of care is akin to adult fostering has been highlighted by the Department of Health (DOH), when defining SL as: “Similar to fostering, but for adults, it is a highly flexible model and services can be tailored to meet the needs of a particular area or community group.” (DOH, 2005). In light of this, the existing literature base on the experiences of children of foster carers may be pertinent when exploring the experiences of sons and daughters of SL carers.

2.2.7.2 The experiences of children of foster carers

Although historically an under researched area, there is a growing trend in the literature to recognise the experiences and outcomes for children⁴ of foster carers. Serbinski and Shlonsky (2014) conducted a review of 39 studies exploring the experiences of foster carers’ children. The results highlighted that childrens’ relationships with foster children were similar to those found in sibling relationships, in that there was a mixture of both positive and negative effects. Children reported enjoying spending time with and helping their foster siblings, as well as engaging in surrogate parenting tasks. They reported feeling pride in their parents for taking on a caring role. However, this was counterbalanced with feelings of jealousy and

⁴ The term children is used to refer to foster carers biological, adopted and step children.

resentment at sharing both their physical space and parents' time with their foster siblings. The experience also affected their relationship with their parents, making them less likely to express their true feelings about the process. In light of the findings, Serbinski and Shlonsky (2014) argue that greater consideration should be given to the needs of foster carers' children. Aside from completing safeguarding measures such as the DBS⁵ check, there are no policies to guide their involvement in the foster family and therefore their needs and experiences are often overlooked.

2.2.8 Overlooked by policy

Through reviewing the literature into SL, it is apparent that sons and daughters of carers are similarly excluded from policies and guidelines. In their 2005 guidelines for placements, the Social Care Institute for Excellence outlines the need for a rigorous and person centred matching process. Although the importance of matching SL users to families who can best meet their needs and wishes is emphasised, no consideration is given to the sons and daughters of carers who may be a part of this family. It could therefore be argued that much like the children of foster carers, sons and daughters of SL carers are the forgotten family members, who have been overlooked in both the literature and the policies surrounding SL.

The need to consider the wellbeing of the wider family or support network around people was highlighted in the Draft Care and Support Bill, which emphasised "the importance of achieving a balance between the adult's wellbeing and that of any friends or relatives who are involved in caring for the adult;" (DOH, 2012, p. 28). In light of this, it seems critical to better understand the potential needs of the sons and daughters of SL carers who may also be part of adults wider support networks.

⁵ DBS or Disclosure and Barring Service check provides a review of a person's criminal record in order to ascertain their suitability to support vulnerable people.

2.2.9 Rationale for the proposed research

Given the paucity of literature in this area, the aim of this research is to better understand the lived experience of sons and daughters of SL carers. Despite the emphasis placed upon the benefits of family based care, there is no current research focusing upon the experiences of family members other than the SL users and carers themselves. It is hoped that by exploring sons and daughters' experiences, this can provide a foundation for future research, inform policy and shape practice within SL.

2.2.10 Research aim

The present study aims to explore and understand the lived experiences of sons and daughters of current or past SL carers who support adults under the SL scheme.

2.3 Method

2.3.1 Design

Interpretative phenomenological analysis (IPA) was the qualitative approach taken in conducting the research. IPA is phenomenological; it places the individual at the centre of their lived experience (Cohen & Omery, 1994). Furthermore, IPA recognises the interpretative process that takes place when research attempts to make sense of an individual's experience. In light of this, IPA was felt appropriate to explore the lived experience of sons and daughters of SL carers. The principles of IPA guided the research throughout the process of conducting semi-structured interviews, transcribing and interpreting the data and steered the researcher's self-reflexive stance.

2.3.2 Participants

A purposive sample of eight participants was recruited from SL services. It was felt that this sample size would allow for a point of saturation in the data to be reached, whilst ensuring that the subtle meanings and richness of participants' experiences was not lost (Smith, Flowers & Larkin, 2009).

2.3.2.1 Inclusion criteria

Participants who were over 16 years of age and whose parents either currently or previously supported an adult within the SL scheme were recruited. Participants who had subsequently taken on the role as a registered SL carer were also included. All participants were able to give informed consent and spoke English fluently, thus meeting the inclusion criteria.

2.3.2.2 Demographic information

Five female and three male participants took part in the interviews, ranging in ages from 20-53 years old (Mean= 32.38). All participants had experience of their parent/s caring for adults under the SL scheme. It should be noted that two participants are related and therefore this is reflected in their accounts of childhood, which at times overlap. All eight participants were of White British ethnicity. Three of the participants were registered SL carers, while six out of eight participants currently shared their homes with SL users. The exceptions to this were Zoey, who as a registered SL carer was waiting to be matched with an SL user, and Charlie who had moved out of the home in which his mother cared for SL users. Further information regarding participant's current carer status and employment are summarised in Table 2.1.

Table 2.1 Participant demographic information

Participant	Age	Gender	Ethnicity	Current carer status	Employment
Ian	35	Male	White British	Parents are the registered SL carers: he currently shares his home with SL users.	SL support carer.
Mary	53	Female	White British	Registered SL carer: she currently shares her home with SL users.	Registered SL carer.
Sarah	38	Female	White British	Husband is a registered SL carer: she currently shares her home with SL users.	Teacher.
Paul	20	Male	White British	Mother is the registered SL carer: he currently shares his home with SL users.	Student.
Katherine	22	Female	White British	Parents are the registered SL carers: she currently shares her home with SL users.	Carer in a residential home (not SL).
Charlie	39	Male	White British	Mother is the registered SL carer: he no longer lives in this house.	Paramedic.
Laura	27	Female	White British	Registered SL carer: she currently shares her home with SL users.	Registered SL carer.
Zoey	25	Female	White British	Registered SL carer: she is not currently sharing her home with SL users but awaiting a referral.	Registered SL carer.

2.3.3 Procedure

2.3.3.1 Ethical considerations

Ethical approval for the research was granted by Coventry University prior to the start of the research (Appendix B). Approval to recruit participants via SL branch managers was also gained through contacting the SL Carer Support and Development Worker. Informed consent was obtained from participants, prior to taking part in the research, via a consent form (Appendix D). Participants were given the opportunity to discuss questions prior to and following the interview and were reminded of their right to withdraw their data from the research until the 1st January 2015. In light of the sensitive and potentially emotive subject area, the debriefing

form outlined contact details of support services. Sensitive data obtained via the interview was anonymised through the use of pseudonyms and once transcribed and coded, original audio recordings were destroyed.

2.3.3.2 Materials

In collaboration with the research team, a semi-structured interview schedule was developed in line with guidelines by Smith et al (2009). The schedule included eight questions and was designed around the central premise of IPA; enabling participants to tell their own story in their own words (Smith et al, 2009). The questions aimed to explore participants' general experiences as well as focusing on both positive and negative aspects of their experiences (Appendix F).

2.3.3.3 Recruitment

The initial stage of recruitment involved contacting SL branch managers from three locations in order to discuss the research aims. Managers then distributed participant information sheets to the sons and daughters of SL carers, which outlined the aims and procedures of the research (Appendix C). The sheet included a consent slip that interested participants signed and returned to the researcher.

2.3.3.4 Interview procedure

The interviews took place from June to September 2014 and were carried out by the lead researcher. All interviews took place at participants' homes or on the premises of SL branch offices. All participants were interviewed separately, with interviews lasting between seventeen minutes and one and half hours. The interviews were audio recorded using a Dictaphone. Following the interview, participants completed

a demographic information sheet and were then debriefed. Appendix G outlines the debriefing information form discussed with and given to participants.

2.3.4 Analysis

The interviews were analysed using the stages adapted from guidelines by Smith et al (2009). The stages of this process are summarised in Table 2.2 (Appendix H).

2.3.4.1 Researcher's position

The researcher is a current trainee clinical psychologist employed by a local trust and also the daughter of a SL carer. The researcher's role as a trainee clinical psychologist may possibly have influenced participants' expectations and/or responses during the interviews. In light of both this and the researcher's personal connection to the research aims, it was crucial to remain aware of this position throughout the process. In line with suggestions by Beech, (1999) two bracketing interviews were conducted both prior to the interviews and the analysis. A diary was also kept throughout in order to support reflexivity. This process revealed the researcher's preexisting assumptions, such as anticipating participants need for further support.

2.3.4.2 Credibility of analysis

In order to ensure credibility of the data analysis, a process of consultation took place both within the research team and with peers. An IPA group was formed during the coding stage and transcripts were discussed with two fellow trainee clinical psychologists also conducting qualitative research. Through group discussion, ideas for both codes and themes were compared and contrasted. A five page section of a transcript was independently coded by a group member.

Consultation around the final emerging themes then took place within the research team, to ensure that the themes selected best reflected participant's lived experiences.

2.4 Results

Three main themes emerged from the data analysis, these superordinate themes and corresponding subordinate themes are summarised in Table 2.3 'Start of a new chapter' is the first superordinate theme and represents participant's understanding of beginning SL; exploring how their family ethos and circumstances influenced this. The second theme is 'Part of the family: building relationships' and represents how participants describe and make sense of their relationships with SL users. The final theme of 'Ambivalence' captures participants mixed feelings around the process of accepting and adapting to SL users. It highlights participants' difficulties in witnessing discrimination against SL users and the personal growth they have taken from this. Finally participants' reflections upon their need to disconnect from the experience are captured.

Table 2.3 Superordinate and subordinate themes

Superordinate Themes	Subordinate Themes
Start of a new chapter	The family that cares The way the story goes
Part of the family: building relationships	Family grows from familiarity Reciprocity Conditionality & impermanence
Ambivalence	Acceptance, resentment and adapting Learning not to judge a book by its cover A need to disconnect

2.4.1 Theme 1. Start of a new chapter

Across seven participants' accounts of the beginning of their families' journeys into SL, there was a collective sense that this marked a new chapter in their families' lives:

"it just closes that chapter and then start a new chapter isn't it."
(Sarah; 572)

Four participants described this new chapter growing from and contributing to a family ethos of caring for others. Five participants reflected that the journey started with an open house; in this way SL felt like a natural progression. The need for change and a significant family event were also described by four participants as catalysts for the decision to join SL.

2.4.1.1 The family that cares

Four participants described how their parents' caring natures or role in supporting others preceded their decision to join SL. Katherine and Ian's mothers worked as carers while Charlie's mother was a social worker and viewed SL as a way of *"continuing []⁶ the caring profession"* (Charlie; 2). Mary conveyed a sense of pride when describing how supporting SL users was an extension of her parents' compassionate nature and desire to help others:

"Because mum and dad have always been really supportive of people you know and I think, that's [] the type of people they always have been."
(Mary; 79)

Four participants described how being part of SL developed their family ethos of caring for people, which subsequently passed through generations of their family.

⁶ [] indicates that irrelevant material such as hesitations in speech, has been omitted.

Zoey and Laura are registered SL carers and spoke about how their experiences of growing up in a home with SL users influenced their career choices:

“I did that [work experience] at a centre for people with learning disabilities because it was always something that, I sort of cared because of [] growing up with it.”

(Laura; 317)

Zoey and Charlie described how their sisters also work in the social care sector. Zoe reflected “we’re all in there” (23). Katherine and Charlie’s experiences influenced their careers as a carer in a residential home and as a paramedic respectively:

“I think it made me who I am because I’m a carer now so”

(Katherine; 77)

A sense of duty to continue supporting the adults in the home emerged in three participants accounts. Katherine described how her grandmother had originally supported older adults at her home, before her mother took over. Mary also inherited the role from her parents, describing it as the “right thing to do” (161).

The sense of duty to continue supporting people is typified by Charlie’s current dilemma following his mother’s decision to retire from SL:

“Daniel, because he’s been with us so long he’s definitely part of the family, to the point where we’ve discussed having him here [in Charlie’s home][] I’ve discussed it with my wife and she doesn’t know because we’ve just had a baby”

(Charlie; 116)

2.4.1.2 The way the story goes

This subtheme represents the divergent ways in which participants made sense of the beginning of their experiences of SL. Five participants described how their family has always been open to welcoming others in, conveying a sense of ‘the more the

merrier.’ Four participants spoke of how changes in their parents’ careers and relationships were catalysts for beginning SL.

Prior to starting SL, Mary’s parents ran a large hotel, while Ian’s family home provided bed and breakfast accommodation. Because of these experiences, Mary and Ian both explained that the progression to supporting SL users in their homes was not a dramatic change:

“the hotel was 20 bedrooms so [] it wasn’t a surprise, so it seemed to be a natural progression”

(Mary; 69)

Laura and Zoey both had experience of growing up in pubs and were used to living in a place where the lines between their parents work and home blurred. Charlie’s mother was a social worker and as part of her role she would open up family life to children she was supporting:

“she did a lot with the children, we used to go on a lot of trips out for the day with them and stuff and yeah. And we used to have them.”

(Charlie; 190)

The open door policy to Ian’s family home was extended to friends, suggesting that this set the scene for their home to then be opened up to SL users:

“we’ve always had people come in and going, a big house everyone’s welcome sort of thing and even at school with friends [] it’s ah, can Joe Blogs stay? Yeah no problem.”

(Ian; 460)

Four participants made sense of the start of a new chapter with SL in the context of a need for a change of career or by a family crisis, creating a problem that needed to be solved:

“the way the story goes is [] my mum and dad separated when I was 14”

(Charlie; 22)

Three participants spoke of how their families had been fractured through their parents' separations. This appeared to be intrinsically linked to the participants' narratives regarding the beginning of SL, overshadowing their experiences. Laura's response to a question regarding whether she had expectations about the first SL user joining their home highlights this:

"it was more about not living with my mum for the first bit. It wasn't necessarily to do with any service users or anything like that"

(Laura; 66)

There was a sense that this time marked a dramatic upheaval for the family, impacting upon participant's wellbeing:

"If there was a time in my life if I could ever say I was off the scale a little bit it was definitely that time."

(Charlie; 24)

SL provided a way out of less favourable careers for Charlie, Sarah and Laura's parents. Laura used the phrase *"get out of"* (56, 64) twice when describing her family's decision to leave the pub trade, emphasising the pressure that this previous job was placing upon the family at the time.

Sarah conveyed her family's desperation at the thought of losing their home due to financial difficulties following her father's death. Her family's decision to care for people in their home was motivated by this and viewed as necessary in order for the family to survive:

"we had to do anything before so we were prepared, we knew the consequences and what we had to sacrifice."

"that was paramount; we had to keep the house."

(Sarah; 46, 50)

The theme of 'Start of a new chapter' captures participants' diverse experiences regarding the beginning of their journeys into SL. It highlights the ethos of caring

and desire to welcome others into the home that is present in some families, as well as some of the potential catalysts for their progression into this career.

2.4.2 Theme 2. Part of the family: building relationships

Seven out of eight participants used the phrase “part of the family” when defining their relationships with some SL users. For six participants, experiencing an SL user as part of the family developed over time out of a process of familiarity. The importance of reciprocity in relationships was highlighted by six participants. Finally, seven participants discussed the conditionality of SL users place in the family home.

2.4.2.1 Family grows from familiarity

Six participants spoke about how SL users had become part of the family due to a growing sense of familiarity. The length of time they had lived with the family, the experience of sharing in family life, or their constant presence, all contributed to participants sense that SL users felt akin to a familiar family member.

Mary could not remember family life before SL users arrived creating a sense that they had become so familiar they were enmeshed in her experience of family life as a whole:

“They’ve always been part of mum and dads life since I was 18 so I don’t remember a time, a real clear time when they weren’t around [] it just seems natural, they’ve always been part of the family.”

(Mary; 178)

Charlie and Ian explained that the SL users had become part of their family due to the length of time that they had been living there:

“Daniel, [] because he’s been with us so long he’s definitely part of the family”

(Charlie; 116)

This time led to a sense of familiarity and knowing one another:

“he’s been there with us so long and he knows us as well as we know him now I suppose.”

(Ian; 197)

Zoey explained that she found it hard to imagine her mother’s home without Danni, an SL user in it, describing her as *“just part of the house”* (85). Through Danni’s constant presence in the home, a sense of familiarity and closeness developed in their relationship:

“Just because she’s been in our lives so long. [] Like my mums got another lady that lives with her and she’s only been there since the beginning of this year and I wouldn’t say I feel as close to her as Danni”

(Zoey; 89)

Laura and Zoey both explained that sharing in routine family activities and events was also part of developing familiarity and a sense of family membership:

“we’ve had holidays together and things like that and she’s always been there so she is sort of part of our family really”

(Laura; 80)

“It was just like living with an extended family, we’d all sit and have dinner together”

(Zoey; 109)

2.4.2.2 Reciprocity

Sarah, Charlie, Mary, Laura, Paul and Zoey described the importance of reciprocity in their relationships with SL users; emphasising the importance of being able to share in affection, humour, positive experiences and a sense that SL users are giving back to family life. Zoey described feeling closer to Kath, a SL user with Down Syndrome, because of the reciprocal nature of their affectionate relationship:

“I just think the loving nature about her, [] the way she was towards me and my family and my mum. She’d tell you she loved you and yeah she was just really really sweet.”

(Zoey; 171)

Charlie explained that he felt close to Beryl, an SL user, because of the humour and fun they would share in. He recalled memories of her with affection:

“She was lovely and she used to make me laugh and like so you’d walk past and she’d blow a raspberry or something [] or she’d throw like a pillow at you or something like that [] So you’d pick the pillow up and throw it back.”
(Charlie; 92)

Out of this reciprocity came a feeling of family membership as Charlie experiences Beryl as like a sibling:

“I used to tell everybody when I was, arr Beryl’s my sister.”
(Charlie; 90)

When reciprocity was missing from a relationship, Zoey felt less close to an SL user despite their familiarity:

“I even felt closer to her than I did with the man that I had for three years. [] Because his personality was another one of those that, he had no interest in anything or anybody but himself, it was all about him.”
(Zoey; 175)

Paul described his disconnected relationship with SL users due to an absence of reciprocity. He explained *“They’re never the one to start a conversation”* (143) and so he does not speak with them unless this is necessary. Sarah emphasised the importance of feeling as though SL users are taking part and contributing to family life:

“I’ve probably got as better relationship with Sam than I have with Reg. Because he will come out, he will go shopping [] he’ll water the garden [] he does things.”
(Sarah; 473)

Sarah expressed resentment towards a SL user who she felt did not contribute to family life in this way, explaining:

“you can’t keep taking and taking, you’ve got to give something back”

(Sarah; 477)

2.4.2.3 Conditionality and impermanence

Seven out of eight participants spoke about their awareness of SL user's impermanence within the family and the conditionality of the placement. Five participants explained that SL users may leave the home due to difficulties with the SL users 'fitting in' with the family, or an increased level of risk associated with their behaviour. A further five spoke of their awareness of SL users' mortality.

Sarah, Laura, Ian, Zoey and Charlie spoke about importance of SL users fitting in with the people in their family including other SL users who live there:

"he's great, you know he does his own thing, you know fits in beautifully"
(Sarah; 606)

Participants were aware that if SL users no longer fit in with the family, then they may be asked to leave:

"I can't remember much all I remember is that after a while they became, mum and Nana basically had enough of them."
(Paul; 60)

There was a sense that if SL user's behaviour changed, biological family's wellbeing and safety was prioritised:

"she smashed like a door window in my mum's house through aggression and because my mum had us there, she couldn't stay there, because my mum couldn't put us at risk."
(Zoey, 99)

As was the safety and welfare of other SL users in the home:

"Obviously there was Danni [SL user] that was living there as well. You don't want to put anybody in danger."
(Laura; 112)

Charlie explained that the decision to ask an SL user to leave was difficult, particularly as he had been close to her. He spoke of needing to create distance in his conceptualisation of the relationship in order to manage this:

“[sighs] you could easily fall into the trap of Beryl at the time just counting her as one of your sisters really she was that close [] it was quite sad near the end when she got a little bit problematic [] when Beryl left us really that was under a heavy heart for my mum. Her mind set was changing she was pinching and she was grabbing”

(Charlie; 60)

In contrast, Ian expressed relief to say goodbye to an SL user who the family found difficult to support:

“we said like no enough enough now he was becoming more awkward and playing on different things so we, the line was drawn and he won’t be coming for respite again.”

(Ian; 407)

This awareness of impermanence and conditionality is what separated participants’ relationship with SL users from their biological family, as Laura’s explanation highlights:

“if their [SL users] behaviours changed or anything changed, my family is a constant and they’re not particularly, at the moment they’re a constant, but I know it might not always be the case.”

(Laura; 345)

Five participants also spoke about their difficulties when SL users died, describing it as “a shock, it was sad” (Charlie; 64). Laura and Sarah recalled the upset experienced by the family when SL users died at home. Sarah described the impact of one such experience:

“Shocking, because [] he was in a right mess obviously he choked on his own vomit, and mum was going in, [] and trying to revive him”

(Sarah; 519-521)

For Zoey the death of a SL user was particularly difficult due to the close nature of their relationship:

*“I’ve never had anybody close to me pass away. [] that was really difficult”
(Zoey; 163)*

Katherine described how this awareness of SL user’s mortality, particularly if they were older adults, impacted upon the closeness of her relationships with them. She described distancing herself from SL users in order to protect against this loss:

*“you just put your guard up a bit. [] as much as it’s a bit heartless
sometimes you think oh it’s just work. It’s just another one; it’s not your
family”*

*“if you put your heart into it and [] a lot of people pass away then you’re
just not going to last.”*

(Katherine; 207 & 209)

This need to create emotional distance highlights Katherine’s awareness of impermanence and the impact this had on her relationship with SL users. It also draws links with a subsequent subtheme outlining participants need to disconnect. The theme of ‘Part of the family: building relationships’ highlights the importance of familiarity in participants’ conceptualisation of their relationships with SL users. Participants outline the conditionality of SL users ‘fit’ within the family home and the transient nature of some relationships. Participants’ awareness of these issues impacts upon their willingness to form meaningful attachments with SL users.

2.4.3 Theme 3. Ambivalence

Participants’ ambivalence in accepting and adapting to being part of SL are reflected in this theme. It highlights how some participants express resentment and others acceptance of their experiences. These opposing stances are also found within individual participants narratives. All participants highlight their ambivalence in

needing to accept and adapt to being part of SL. Six reflect upon the rewards and difficulties in learning a non-judgemental attitude. Finally eight participants discuss their reasons for emotionally or physically creating space within their experiences.

2.4.3.1 Acceptance, resentment and adapting

This subordinate theme reflects the sense of acceptance and resentment woven throughout participants' experiences. This is evidenced in their feelings regarding the initial decision to join SL and their approach to day-to-day family life. It is also highlighted in participants' accounts of needing to adapt to SL users.

Sarah and Katherine were the only participants who were actively involved in the families' decisions to be a part of SL. For the remaining six, the decision was made by their parents. There was a sense that participants had no choice but to accept this, even when not fully understanding it:

“it was quite confusing for us in a way because. [] just being so young we didn't have much say in it, it was mum and dads choice and I think we were too young to understand what was happening”

(Zoey, 71)

Charlie reflected upon how he made sense of SL users moving in the home, remembering:

“mum said Beryl's coming to live with us and I presumed at the time it was for an income really”

(Charlie; 30)

Similarly, Paul was simply told *“that someone's going to be living with us”* (30), suggesting that all three participants had no part in the decision to support SL users in the home.

Although Mary supported her parent's decision, she described feeling hurt upon discovering her bedroom had been adapted in this process. Despite this, she minimised her distress and took a pragmatic view to help her to accept the situation:

Mary *"I came home and where's my bed? It's a kitchen!"*
 Researcher *"What was that like?"*
 Mary *"It was quite umm okay. Right needs to be done yeah. It was quite sort of uh! I wish somebody had said"*
(Mary; 42-44)

In contrast, Sarah felt that sharing her home with SL users has been imposed upon her. She had no choice and this led her to feel resentful towards SL users:

"maybe I resent them sometimes"
"I have to have them in. There isn't a choice, and I don't think from 14 until now there has never been a choice"
(Sarah; 546 & 548)

Four participants spoke about accepting the cyclical nature of SL users entering and leaving their homes. As Laura became resigned to the revolving door of people, her interest in getting to know the SL users who arrived faded:

"I probably made a bit of an effort with Danni because she was the first one and it was something new []. But then every person after that it was a bit like, it's just somebody else"
(Laura; 178)

Katherine and Ian adopted a pragmatic acceptance of new people into the home, explaining *"it's just another person staying with us"* (Ian; 271). Due to the regularity of people entering and leaving the home, Katherine easily accepted SL users:

"If one kind of goes another one comes in. [] it was fine, I didn't think much to it really."
(Katherine; 59)

This pragmatic acceptance was mirrored in Sarah, Paul and Ian's descriptions of daily life as part of SL. Sarah accepted the expectation that she would *"muck in"* (98) and help out with household tasks. Ian used the phrase *"second nature"* (329,

341, 365) when describing supporting SL users in the home. He does not question this part of life but adopts an attitude of *“just get on with things”* (405).

Although participants spoke of accepting family life, they also recognised that the need to adapt was a more negative aspect for them personally. The different ways in which family life was restricted are summarised by Sarah:

“No we can’t go on holiday, no you can’t walk around your house butt naked, because you can’t do it. You can’t lock, unlock your loo door, you can’t just go out straight away”

(Sarah; 589)

Katherine, Charlie and Sarah spoke about how they had needed to become more discreet in their home since the arrival of SL users, adapting their behaviours:

“my sisters would walk around the house in our underwear []. And obviously you’ve got to curb that when there’s a guy in the house”

(Laura; 108)

Charlie felt that he needed to censor what he said in the house and behave in a professional manner with SL users, for fear of negative repercussions. His mother would need to remind him of these new rules:

“you’ve just got to be careful [] Mum would always like you know, you can’t say things like that because. You can if it’s your own brother and sister. So maybe that was probably the difficult part of that”

(Charlie; 52)

Katherine and Sarah highlighted the need for greater organisation and reduced spontaneity in family life. Katherine’s ambivalence in adapting to this is apparent when she explains:

“it can be frustrating [] but it’s just one of them, you get through it.”

(Katherine, 123)

Laura felt guilty for struggling to accept some aspects of life with Eddie, an SL user who had schizophrenia. She described how she disliked watching him eat dinner, describing it as “*slurpy*” (126). Her guilt reflects an awareness that she needs to minimise her feelings and accept Eddie:

“you feel really bad [] I’d rather not sit at the table and eat with him.”
(Laura; 132)

Zoey, Mary and Katherine described how they accepted caring for SL users as being part of their normal life:

“it’s just normal to me I don’t know any different”
(Zoey; 45)

Zoey and Katherine were eight years old when their family began to care for SL users. Although Mary was 18, her family had supported SL users for the majority of her life. Their conceptualisation of SL as part of normal life suggests that acceptance may be a process that is easier when family life has not been any different:

“you just grow into where you are []. I think if you were older, say maybe my older brother’s age, he would have been 11 so it might have been that bit harder for him”
(Katherine; 229)

2.4.3.2 Learning not to judge a book by its cover

Five participants discussed how other people outside of the family had a judgemental attitude towards the adults their families supported due to their disabilities. These experiences of witnessing discrimination were difficult for participants. However, six participants describe a process of personal growth from these experiences, in learning to become non-judgemental.

Mary and Katherine spoke about their anger at people’s judgemental reactions to SL users. Mary describes her disappointment at negative reactions to SL user’s decision to get married:

“disappointing and also annoying, you immediately want to jump to defence”

(Mary; 93)

Katherine emphasised her distress when witnessing other people stare at an SL user who lived with her. Coping with other people’s judgements was a process that developed over time:

“I get used to it now, at first I was going to my mum, I don’t like it, I don’t, I don’t like people staring at her”

(Katherine; 175)

Sarah and Laura both describe finding other people’s negative judgements of SL users difficult. They managed this by initially keeping this aspect of their life hidden from their friends:

“It wasn’t good, I didn’t tell friends, because [] you don’t publicise the fact that you live with a nutter”

(Sarah; 86)

Sarah, Katherine and Zoey reflected upon peoples shock and surprise when learning how their family cares for people with disabilities. Katherine described feeling annoyed at people’s judgements that supporting adults in her home is “weird” (155):

“I think it gets your back up a little bit sometimes [] you think no there’s nothing different.”

(Katherine; 157)

Laura describes the positive impact that her experience of witnessing people’s negative reactions had, in developing empathy for others:

“I think it makes you more caring. [] you feel for people more.[] Because we’ve had to like deal with like, especially when I was younger [] No embarrassment but people actually calling people names”

(Laura; 355)

This change in perception of difference also extended to Laura’s social networks:

“they were my friends and they were around these people that had got learning disabilities and they realised that it’s not something to be frightened of.”

(Laura; 48)

Sarah and Mary initially felt frightened of people due to their disabilities or appearance. Mary described meeting Terry, one of the first adults who came to stay with her family. Terry had a facial deformity and Mary explained that despite her initial shock, she began to understand that Terry's appearance did not reflect his gentle nature. She spoke of Terry with affection and was left with a non-judgemental attitude, exemplified by the phrase 'don't judge a book by its cover':

"Yeah I can still visualise him, very kind [] you could sit and have a chat with you and he would just look up to you and put his head on your shoulder and he was a huge man! He was a huge man! You know as I say but it did teach me not to judge people not by cover"

(Mary; 139)

Similarly Charlie explained that his experiences had a positive influence on his role as a paramedic. He spoke of other professional's judgemental attitudes towards individuals with MH difficulties, explaining that he does not share these:

"they [his paramedic colleagues] shouldn't be but the empathy's not there it's almost like 'oh God it's another overdose, oh God it's another one of these.' And I'm pretty good at stuff like that"

(Charlie; 212)

2.4.3.3 A need to disconnect

All eight participants spoke about the need to disconnect themselves from certain aspects of life as part of SL or certain SL users; this disconnection was both physical and emotional.

Charlie, Mary, Laura and Zoey discussed the need for their own physical and personal space. Charlie emphasised the importance of having enough physical space in the house to allow him a sense of privacy:

"We moved to this really big farm house and literally it was massive and Dan had his own section of the, it had two staircases, well it had two wings."

(Charlie; 68)

While Mary reflected that personal space is important for “*Everyone in any family*” (8), Ian used physical space as a way of disconnecting from difficulties that arose in his relationship with one SL user:

“to be perfectly blunt I didn’t like him, I tried to. I was out or busy when he was about.”

(Ian; 137)

Charlie, Sarah and Laura spoke about how they felt separate from the experience of SL at certain points in their life. Laura explained that during her teenage years, she spent little time in the house preferring to focus on her peer relationships:

“we were all a bit disjointed from each other because my sister was off [] Me and my younger sister were out with friends quite a lot.”

(Laura; 162)

Similarly, Charlie spoke about feeling separate from the experience during his teenage years, due to a focus on his own goals in life:

“I was quite into my own thing so I’d be what 16 I’d got girlfriends, learning to drive”

(Charlie; 30)

Paul described an emotional detachment from both the experience and the SL users themselves, explaining that he did not notice when the SL users were around because “*they weren’t really anything to do with my business*” (81).

Katherine explained that adopting a relaxed but emotionally disconnected approach enables her to cope with situations that she may not otherwise be able to accept:

“I’ve been getting more laid back but I think it’s just that really, it helps. If you think about it too much, you might not like the situation”

(Katherine; 117)

Laura adopts a similar approach, describing how she emotionally distanced herself during her experience, which allowed her to minimise the impact on her personally:

“it’s not really something that I particularly think about or I don’t really have, like a huge effect. Maybe subconsciously it might have done but I don’t feel like it’s had a massive effect, maybe at the time”

(Laura; 74)

The theme of ambivalence reflects the mixture of emotions participants expressed when describing their life as part of SL and the way they adapted to the challenges of the scheme. It also captures participants’ difficulties in witnessing judgemental attitudes towards SL and the personal development they have taken from this. Finally, participants’ reasons for needing to create emotional and physical distance from the experience are reflected.

2.5 Discussion

2.5.1 Summary of findings

The present study aimed to explore the experiences of sons and daughters of SL carers. Three superordinate themes emerged from the findings; each will be discussed in turn in relation to existing literature. Given the paucity of research into SL, the literature on caring for disabled family members and children of foster carers will be drawn upon.

2.5.1.1 Start of a new chapter

A theme regarding participant’s understanding of the start of their families’ journeys supporting SL users emerged. Four participants reflected that their family ethos of caring had influenced their parents’ motivation to support SL users and subsequently their own careers. Their parents’ previous careers in the care sector and compassionate natures meant that joining SL was a natural progression. This is consistent with previous findings that 88% of SL carers previously worked in the care sector (Young, 1988). Being part of a welcoming home was also an existing

feature of five participants' families. Family crises such as a need for income, career change, or family separation were catalysts for starting this new chapter for four participants. This links to research by Rodger, Cummings, and Leschied (2006) highlighting that foster carers were motivated by both intrinsic factors such as a desire to care for children and extrinsic factors such as increasing the family income, in their decision to foster.

2.5.1.2 Part of the family: building relationships

The diversity within participants' relationships with SL users and factors contributing to this were explored. Six participants conceptualised SL users' part in their family as developing through familiarity, influenced by the length of time they had lived there, their constant presence and part in family life and events. This finding is encouraging in light of the SL aim for carers and SL users to share in family life and events (Shared Lives Plus, 2013a). This suggests that participants' families understand this aim of creating a sense of belonging.

Reciprocity was a key feature of close, affectionate relationships with SL users. Humorous relationships and feeling that SL users were contributing to family life were extremely valued. Three participants felt disengaged from SL users who did not contribute to relationships or family life. This is consistent with research emphasising the role of reciprocity in family relationships of adults with MH difficulties. The amount of support that adults with MH difficulties gave to their families predicted the level of family support they received in return (Horwitz, Reinhard, & Howell-White, 1996).

Seven participants reflected upon the conditionality of SL user part in their family home and life, emphasising the importance of SL users 'fit' within the family. The findings supported previous research, recognising the importance of SL users being

carefully matched with families (Brookes & Callaghan, 2013). Five participants spoke of the difficulties when SL users die. This awareness of SL user's impermanence within the home impacted upon the closeness of relationships, particularly with older adult SL users.

2.5.1.3 Ambivalence

A theme of ambivalence towards accepting and adapting to SL emerged. Six participants experienced a lack of control around the family's decision to care. Participants expressed acceptance and at times, resentment of having less privacy and a greater need for organisation. One participant struggled to express her true feelings regarding her difficulties; a finding also highlighted in the literature on foster carer's children (Serbinski & Shlonsky, 2014).

Five participants discussed the impact of discrimination that SL users face. Two participants kept SL users separate from their peers for fear of judgement. However, these experiences enabled participants to develop a non-judgemental attitude that is accepting of difference. Dautz Williams, Piamjariyakul, Graff, and Stanton, (2010) explored the relationship between siblings with a LD and those without, finding that non-disabled siblings report similar mixed outcomes. They experienced embarrassment amongst peers, whilst also developing increased acceptance and understanding of people with disabilities.

All siblings reported disconnecting from their experiences particularly at times of difficulty, or when focusing upon their own lives outside of the home. This parallels findings in research into adult siblings of people with LD. Non-disabled siblings reduced their involvement with disabled siblings as they established their own adult lives (Davys, Mitchell & Haigh, 2010).

2.5.2 Limitations

The present study is limited by the small sample size used. All participants are of white British ethnicity, making the findings difficult to transfer to the wider population of sons and daughters. Furthermore, the findings are culturally bound to the UK, in which the model of SL is based.

The inclusion of sons and daughters who are currently SL carers is a further limitation of the study. Although the researcher was careful to only include participants' experiences of their parents caring for SL users in the findings, participants' narratives were inevitably influenced by their current roles. SL carers may have additional agendas, with several expressing their desire for SL to be promoted and the value recognised. These participants may have been more susceptible to the influence of social desirability bias.

The central premises of IPA are enabling participants to tell their own story in their own words, whilst acknowledging the researcher role interpreting their experiences (Smith et al, 2009). The researcher's reflexivity on her position and triangulation of findings within the research team, has added to the credibility of the findings. However, it is possible that the researcher's assumptions that participants would highlight the need for support, have influenced the interpretation of the findings.

2.5.3 Clinical implications

Serbinski and Shlonsky (2014) highlight that foster placement length and stability is influenced by the impact it has upon sons and daughters of foster carers. The present study highlights that participant's safety is also a crucial factor in the conditionality of SL users placements as is SL users general 'fit' and relationships with the family. Sons and daughters of SL carers may benefit from being more involved in the initial assessment of family suitability and the 'matching' of SL users with families, given

their sense of a lack of choice and control. Expressing their true feelings may be difficult for sons and daughters and so professionals involved in the matching process must pay particular attention to understanding their needs.

Ongoing support for sons and daughters to build positive relationships and manage any difficulties in adapting to SL users is important in order to maintain placement stability. Training for SL carers on how to maintain family life and balance the needs of both the family and SL users, may also be appropriate.

Support around loss and bereavement may be helpful for some sons and daughters, particularly in light of recent research promoting the role of SL in caring for older adults (Brookes & Callaghan, 2013).

Good practice guidelines for supporting young carers, highlight the benefits of children having time away from the home to engage in recreational activities with others in a similar situation (Ronicle & Kendall, 2011). Given sons and daughters need to disconnect from family life, groups offering recreational activities away from the family home may provide more time for personal space.

2.5.4 Areas for future research

The current findings focus on adult children of SL carers. Future research may wish to explore the experiences of SL carers' children under 16 years old, particularly given research outlining the emotional conflict that children of foster carers can experience (Serbinski & Shlonsky, 2014).

The findings highlight the differences in participants' relationships with SL users, pointing towards reciprocity as a mediating factor. Future research exploring the reciprocity between families and SL users may be useful in order to promote positive and supportive relationships. Research by Kaminsky and Dewey (2001) highlighted that siblings of individuals with Autism Spectrum Disorder (ASD) reported less

intimacy in their sibling relationships, than siblings of individuals with Down Syndrome. The authors pointed towards the difficulties in engaging in reciprocal relationships associated with ASD, when accounting for the findings. Future research may therefore benefit from considering SL users type of disability when exploring reciprocity within relationships.

In light of participants need to disconnect from SL and the resentment they may feel, future research focusing upon sons and daughters coping strategies would be beneficial.

2.5.5 Conclusion

SL is a widely used model of care, which is under represented in empirical literature. The present findings suggest that future research would benefit from continuing to consider SL in the context of the carers' wider family, acknowledging families' valuable roles and the impact upon sons and daughters.

2.6 References

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CHAPTER THREE: REFLECTIVE PAPER

Whose story am I telling?

Reflections upon my personal connection to the research

This paper has not been prepared for submission to a journal.

Chapter Word Count (excluding footnotes and references): 2,605

3.1 Introduction

This chapter outlines my reflections on the process of conducting my empirical research into the experiences of sons and daughters of Shared Lives (SL) carers. It draws upon ideas from a reflective diary that I have kept throughout the research process. I discuss my struggle with conducting research that has such a clear personal resonance, reflecting upon similarities between my own experiences and the experiences of participants. These parallels inevitably helped me to make sense of my own experiences. However, I point towards my anxieties around this, such as wanting to ensure that I have been telling the participant's story and not my own. Finally I draw upon Narrative Therapy to present my story of the research experience, encompassing both the challenges and rewards it has brought about for me.

3.2 In search of a family tree

When I initially embarked upon this research I approached it with some hesitation, questioning whether others would share my curiosity to understand the experiences of sons and daughters of SL carers. It certainly was not my first choice of research topic. Although it crossed my mind, it was quickly disregarded for being too obvious, self-indulgent or perhaps too close to home; after all, these were experiences that I had also shared. My parents began to care for adults under the SL scheme when I was six years old and continue to do so. Indeed SL is now so enmeshed within my family that it cannot be separated out from my experience of life. It is undeniable that my desire to make sense of others' experiences was ignited by this. Just as people discover themselves through searching for their family tree, perhaps I was in search of a greater understanding of my own experiences through my research.

3.2.1 A process of normalisation: “I’m always surprised by how surprised others are”

Reflected in the title is a quote taken from the journal that I kept throughout my journey into the research. Upon reviewing my journal I was struck by the resonance of this reflection, with feelings shared by several of the participants in the study. Along with some participants, I share the sense that being part of SL is a form of ‘normality’ for my family and therefore it is hard to comprehend others shock or surprise at this. During the interviews participants frequently expressed annoyance and resentment at this; perhaps revealing that the suggestion there was something abnormal about their family life was too much to bear. I wonder if in a similar way, I too sought to normalise my own experience through choosing to conduct this research and hearing the stories of other people who had shared in these.

3.3 Whose story am I telling?

“Whose story is it- the researcher or the researched?” (Pillow, 2003, p.176).

My ambivalence towards my personal connection to the topic of my research is something that I have carried throughout the process, particularly now as I reflect upon it. I have been very aware of my position as a researcher. As much as I have been curious about possible commonalities between my experiences and the findings, and aware of my desire to normalise my experiences, I have been mindful of not wanting to ‘research’ myself in this process. However, there have been times that I have felt my closeness to the research has been beneficial. My prior knowledge of the area eased the recruitment process and enabled me to build rapport easily with participants.

There is an assumption held in qualitative research that the author’s self-reflexivity and transparency of their subjectivity through disclosure, leads to greater validity of

the findings (Pillow, 2003). Given the lack of previous literature in the area, I am clear that my research question was driven by my own personal experiences.

Delgado Bernal (1998) argues that through sharing in commonalities with the population being researched, researchers are able to adopt an insider perspective known as cultural intuition. It is argued that drawing upon researchers' personal experiences and prior knowledge adds a theoretical sensitivity to the research (Calderón, Bernal, Huber, Malagón, & Vélez, 2012).

3.3.1 Confessing my position

In contrast to the idea of cultural intuition, Pillow argues that simply writing a “confessional tale” of how the researchers experience has influenced the findings, does not render them anymore valid (2003, p.183). She outlines that there are pitfalls in seeking similarities between oneself as a researcher and participants; finding commonalities should not be misconstrued as understanding another's point of view. This is a position that I have found myself feeling wary of and, at times during the research, I have felt that my personal connection has restricted me, making me work harder to check my assumptions at every step in the process. I have been concerned that my experience may have ‘contaminated’ the process in some way.

On balance, it has not been my aim to use self-reflexivity to affirm my own experiences, nor to justify the steps I have taken to ensure the validity of my findings. Instead I hope to share my own experiences of the research process, highlighting where this overlaps and diverges from the findings. As Peshkin concludes, researchers have a duty to at least outline “where self and subject became joined.” (1988, p.17)

3.4 Acknowledging the difficulties

I have always conceptualised my experiences of SL as being inherently positive. It has undoubtedly influenced my career and prepared me for roles along the way. I take a sense of personal growth from my experiences and feel that it has helped me to develop empathy, compassion and a desire to understand others. It has been much harder to acknowledge the challenges of SL and it was not until I began to engage reflexively with my research that I truly became aware of the difficult parts of my experiences.

As I journeyed deeper into the research process I was aware that hearing participants' stories around the challenges they faced was not always easy for me. My awareness became further heightened throughout the data analysis, as themes emerged regarding participant's resentment and need to disconnect from the experience. I found myself experiencing anxiety around the potential negative impact of the findings upon SL. Curiously it was at this point that I began to be drawn towards exploring the positive experiences of siblings of children with learning disabilities, as a topic for my literature review. Perhaps through this, I sought to counteract the more difficult experiences that were being uncovered in my empirical research.

3.4.1 Censorship

My anxieties around expressing both participant's and my own difficulties in the experience were mirrored in the findings. At times participants minimised the difficulties that they had in adjusting and accepting SL users⁷, suggesting that they felt a need to censor their negative feelings. The need for self-censorship was shared

⁷ The term SL users is a term used by Shared Lives Plus to refer to the adults who are supported under the Shared Lives scheme.

amongst participants as they described needing to adapt the way they behaved with SL users compared to their biological family members. They were reluctant to engage in affectionate teasing, for fear that this would be misconstrued as unprofessional and potentially discriminatory.

My own desire to censor the findings left me feeling uncomfortable when writing some of the participant's more openly resentful or discriminatory comments. I felt caught in a conflict between wanting to capture participants' personal experiences of struggling to accept people with disabilities, whilst feeling professionally concerned regarding the impact of this. Some of the attitudes expressed did not always sit comfortably with me, particularly in my role as a trainee clinical psychologist, in which I value working with people with mental health issues, learning disabilities and physical disabilities. This again led to my awareness of the conflict inherent in my multiple roles as a researcher, clinical psychologist and as the daughter of SL carers.

3.4.2 Conflict: personal vs professional

My own struggles, lead me to reflect upon the apparent conflict participants faced, in relating to SL users as both members of a family and as sons or daughters of professional carers. Every family has its own set of idiosyncratic norms, beliefs and attitudes that may not always fit with those ascribed to by the wider society.

Participants spoke of initially feeling scared of SL users. They were very aware of the general public's judgemental reactions towards people with disabilities, leading them to experience a sense of anger or embarrassment. The language participants used at times highlighted their inherent family judgements around disability, with one participant using the term "*nutter*" (Sarah; 86) to refer to an SL user. I found

myself wondering how these judgements fitted in with the professional world of SL, in which SL users deserve to be cared for with dignity and respect.

Research highlights, that people feel most comfortable expressing negative attitudes towards people with disabilities with people whom they feel closest to and least comfortable expressing these within a place of work (Staniland, 2011). How then do families involved in SL, manage their judgements when their place of work collides with a place in which they are closest to people? Several participants spoke of developing non-judgemental attitudes towards people with disabilities, through a process of challenging their own assumptions and through their experiences of SL users. However, I also wonder if participant's awareness of socially acceptable attitudes and the need for greater professionalism, contributed to their increased sense of acceptance.

3.4.3 Opening up your whole family

As my research progressed, I inevitably started to reflect upon my own personal experiences of SL and how I too struggled with the concept that my family home was also a professional place of work. One participant's comment in particular resonated with me *"you are opening up your whole family aren't you"* (Charlie; 214).

My awareness of these more difficult parts of my experiences, were also influenced by my placement in a Looked After Children's (LAC) service, at the time that I was engaging reflexively with my research. A large part of my role was to provide support to foster carers. The parallels between my experiences of SL and working within the LAC service were something that I was not anticipating. Nonetheless, there were several moments in which I was struck by feeling that I was now 'on the other side of the fence'.

I recall visiting a residential home for children and a member of staff offered to show me around. She reached the door to the bedroom of a child whom I had not previously met and knocked before inviting me to look around. I felt uneasy and concerned that I should be allowed to enter the child's private space so easily. Equally for the member of staff and for me, the residential home was a place of work in which professionalism prevailed. For the child however, this was his bedroom. This experience immediately took me back to my own memories of professionals looking around my home and popping their heads around my bedroom door. My reflections have reminded me that as a psychologist I am privileged to be invited into people's personal lives. However there are also many times when my involvement will be uninvited. My experiences have taught me the importance of being sensitive to the conflict that people face when professional and personal lives collide.

3.5 Constructing the preferred narrative

When I began the process of writing up the findings of my research, I was curious to find that despite the diverse themes that emerged, participants stories about SL always ended on a positive note. Even participants, who had explicitly stated their resentment of being part of SL at times, summarised their experiences by focusing upon the positives aspects for them personally. This drew parallels with the findings from my literature review into the positive perceptions of siblings of children with learning disabilities and I became aware of the value in being able to contextualise difficulties within the rewards that can also be gained.

This led me to think about the model of Narrative Therapy that I drew upon in my literature review. This approach outlines that people make sense of their experiences through constructing narratives to reflect these. Often people can become stuck within their dominant narratives that have been created, therefore shaping their

perceptions or future experiences (Payne, 2000). Difficulties can arise when a dominant narrative is one that is saturated by problems. Narrative therapists therefore encourage people to seek the stories that are untypical of this; thus creating a richer narrative (Payne, 2000). It is through constructing these richer, preferred narratives that people are able to view problems alongside the strengths and positives that also exist. I wonder if in a similar way, the participants in my research were able to accept the difficult parts of their experiences, by also acknowledging the positives.

3.5.1 Concluding my narrative: the researcher and the daughter

Through my research, I have taken pride in revealing participants' rich narratives that include both light and shade in their experiences. I hope that I have been able to represent their voices as truthfully as possible. My research and self-reflexivity around it, has undoubtedly shed light on some of the personal challenges of my experiences of being a part of SL. However, my own preferred narrative has always been one that also encompasses the many positive aspects that having a family which includes SL users has brought about for me personally.

In the same way, the process of completing my research has been both testing and rewarding in equal measures. There have been times that I have felt overwhelmed by the process and doubted my abilities to see it through to the end. Conversely, there have also been times when I have felt immensely privileged to be sharing in participants personal stories and have felt passionate about understanding these. Participants never ceased to amaze me with their honesty and ability to articulate their experiences in a way that I have struggled to. With this in mind, I would like to finish my own story of this research by sharing my most rewarding memory from the experience. It relates to a SL carer whose kindness and commitment to supporting people will always inspire me.

3.5.2 Mighty oaks from little acorns grow

While approaching the end of my journey through the research process, I have been frequently reminded of a reflection from a SL carer following her daughter's interview. The carer had been supporting people in her home for approximately 30 years, before her daughter had taken over the reins. Both mother and daughter spoke with great affection about how they had seen the people living with them change, grow and blossom over this time. Along with the adults they cared for, they took great pride in showing me around their beautiful garden bursting with colour and life. I pointed to two great spruce trees overshadowing the garden. The carer explained that she had found these trees when they had first moved to the house, during a visit to the garden centre 20 years ago; they had been propped up next to the bins. She had rescued them from their fate and brought them home with her. I was taken aback, at how she had been able to revive those trees that had grown into the towering greenery before me. She explained that there was no magic secret; all it took was time, perseverance and love. I could not help but to see the carer's story of the spruce trees as a metaphor for her care and support for the three SL users the family supported. This is the image that I will take away with me; it will forever remind me that through nurture and persistence, great things can grow.

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Appendix A. Table 1.3 Quality checklists

Qualitative criteria	Conway & O'Neill (2004)	Diener et al (2015)	Graff et al (2012)	Hames (2007)	Mascha & Boucher (2006)	Moyson & Roeyers (2012)	Petalas et al (2009)	Petalas et al (2012)	Total criteria score
Does the title reflect the content?	1	2	2	2	2	2	2	2	15
Are the authors credible?	2	2	2	2	2	2	2	2	16
Does the abstract summarise the key components?	1	2	2	2	0	2	2	2	13
Is the rationale for undertaking the research clearly outlined?	2	2	2	2	2	2	2	2	16
Is the literature review comprehensive and up to date?	1	2	2	2	2	2	2	2	15
Is the aim of the research clearly stated?	2	2	2	2	2	2	2	2	16
Are all ethical issues identified and addressed?	2	1	0	1	2	2	2	2	12
Is the methodology identified and justified?	1	2	2	2	2	2	2	2	15
Philosophical background identified and rationale for methodology?	1	2	1	2	2	2	2	2	14
Are all major concepts identified?	2	2	2	2	2	2	2	2	16
Is the context of the study outlined?	2	2	2	2	2	2	2	2	16
Is the selection of the participants described and the sampling and method identified?	1	2	1	1	2	2	2	2	13
Is the method of data collection auditable?	2	2	2	2	2	2	2	2	16
Is the method of data analysis credible and confirmable?	0	2	2	1	1	2	2	2	12
Are the results presented in a way that is appropriate and clear?	2	2	2	2	2	2	2	2	16
Is the discussion comprehensive- are the results transferable?	1	1	2	2	1	1	1	1	10
Is the conclusion comprehensive?	2	2	2	2	2	2	2	2	16
Total (Maximum score=34	25	32	30	31	30	33	33	33	

Quantitative criteria	De Caroli & Sagone (2013)	Findler & Vardi (2009)	Kaminsky & Dewey (2001)	Macks & Reeve (2007)	Pollard et al (2013)	Van Riper (2000)	Verte et al (2003)	Rivers & Stoneman (2003)	Total criteria score
Does the title reflect the content?	2	2	2	2	2	2	2	2	16
Are the authors credible?	2	2	2	2	2	2	2	2	16
Does the abstract summarise the key components?	2	2	2	2	2	2	2	2	16
Is the rationale for undertaking the research clearly outlined?	2	2	2	2	2	2	2	2	16
Is the literature review comprehensive and up to date?	2	2	2	2	2	2	2	2	16
Is the aim of the research clearly stated?	2	2	1	0	2	2	2	2	13
Are all ethical issues identified and addressed?	2	2	1	0	1	0	0	0	6
Is the methodology identified and justified?	2	2	2	2	2	2	2	2	16
Study design clearly identified and rationale for design evident?	1	1	1	1	1	2	1	1	9
Is there an experimental hypothesis clearly stated and variables defined?	2	2	0	2	2	2	2	1	13
Is the population identified?	2	2	2	2	2	2	2	2	16
Is the sample described and reflective of the population?	1	1	1	1	1	1	2	2	10
Method of data collection valid and reliable?	2	2	2	1	2	2	2	2	15
Method of data analysis valid and reliable?	2	2	2	2	2	2	2	2	16
Are the results presented in a way that is appropriate and clear?	2	2	2	2	2	2	2	2	16
Is the discussion comprehensive- are the results generalisable?	1	1	1	1	1	1	1	1	8
Is the conclusion comprehensive?	2	2	2	2	2	2	2	2	16
Total (Maximum score=34)	31	31	27	26	30	30	30	29	

Appendix B. Ethical approval

REGISTRY RESEARCH UNIT ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Rose Brown

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: Part of the family: A qualitative enquiry into the experiences of sons and daughters of carers offering long term family placements to adults under the Shared Lives scheme.

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

Generally this seems to be a well thought through project with regards to ethical considerations. I am left wondering whether 6 participants will or will not provide sufficient data and therefore would encourage the researcher to broaden their limit. Also there is some inconsistency about the number i.e. as I note in the summary section the researcher writes six, however later it is noted that there will be approximately six in another part of the form.

I would have preferred the research questions to be submitted on a separate handout. The wording does seem a little repetitive and would be construed as closed questions and may need altering slightly.

2. Evaluation of the participant information sheet and consent form:

Generally the participant information sheet and consent forms seem well constructed. I would like the researcher to put the actual date when the participant can withdraw from the study onto the consent form as currently it reads as January 2015.

Finally, I would like the researcher to construct a debrief sheet for the participants.

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

<input type="checkbox"/>	Approved - no conditions attached
<input checked="" type="checkbox"/>	Approved with minor conditions (no need to re-submit)
<input type="checkbox"/>	Conditional upon the following – please use additional sheets if necessary (please re-submit application)
<input type="checkbox"/>	Rejected for the following reason(s) – please use other side if necessary
<input type="checkbox"/>	Not required

Name of reviewer: Anonymous.....

Date: 17/02/2014.....

Appendix C. Participant information form

(Headed paper)

Information Sheet

The experiences of sons and daughters of Shared Lives carers offering family placements to adults under the Shared Lives scheme.

Hello,

My name is Rose Brown and I am a trainee clinical psychologist studying at Coventry and Warwick Universities on the Doctorate Course in Clinical Psychology.

I would like to invite you to participate in a research study into the experiences of sons and daughters of Shared Lives carers. This information sheet will outline the purpose of the research and what it involves. Please take the time to read this information before deciding whether to take part.

What is it about?

The research study aims to explore the experiences of sons and daughters of Shared Lives carers who currently or have previously, had experience of sharing their family home with an adult who has been placed under the Shared Lives scheme.

Do I have to take part?

No, participating in the research is voluntary, meaning that you do not have to take part if you do not want to. During the interview, you are free to withdraw without question, if you no longer wish to participate and your data will be destroyed. If after the interview has taken place you decide you do not want your data to be used in the research, you are free to withdraw this up until the date of the 1st January 2015 and it will be destroyed.

What will the research involve?

If you decide to take part in the research, I will initially contact you to agree a time and location that is convenient for you to meet in order to take part in a one off interview about your experiences. Once this has been agreed, we would meet to take part in the interview which is estimated to last approximately one hour. Before we begin, there will be an opportunity to discuss the research and ask any questions. If you are happy to go ahead with the interview, I will ask you to complete a consent form to confirm that you would like to take part.

The interview is designed to ask you about your experiences and there are no right or wrong answers. With your permission, the interview will be digitally recorded to ensure that I don't miss any of your comments; however, everything that you say is confidential and no names will be included in my research.

What happens after the study?

After the interview, I will listen to the voice recording and transcribe what was said in the interview. Only I and other members of my research team will have access to this recording. The transcription will not include any personal identifiable information and your name will be changed to ensure that your identity is protected.

The transcription and the recording will be stored on a password protected computer. Once the voice recordings have been transcribed they will be permanently deleted. Paper copies of the transcription will be kept in a securely locked filing cabinet. They will be kept securely for 5 years, in line with the university data handling policy. The findings from the study will be written up and will form part of a thesis written for the Doctorate course in Clinical Psychology. It is hoped that the results may also be published in a journal, however no personally identifiable information will be included in this. You will be given the opportunity to have a summary of the results of the study upon its completion should you feel that this would be beneficial.

What are the advantages and disadvantages to taking part?

It is anticipated that taking part in the interview may provide a helpful opportunity to share your experiences and to have your views listened to. However, when discussing your experiences it is possible that sensitive or emotive topics may be touched upon. In the event that you do not wish to continue due to this, the interview will be stopped and you are able to withdraw your data. Information on local support services will be available to you.

Who has reviewed the study?

The research study is subject to ethical approval from the University of Coventry and as such, it will adhere to the codes of ethical practice and conduct outlined by the university.

Confidentiality

If you would like to take part in the study, you will be asked to sign a consent form to confirm this. No names or identifiable features will be included in the research and the data will be stored securely.

What happens next?

If you decide that you would like to be contacted about taking part in this research, please complete the slip below and return it to Coventry University in the pre-paid envelope provided

Contact Details

If you would like further information about the study, you can contact:

- Rose Brown, Principal Researcher and Trainee Clinical Psychologist: brownr32@coventry.ac.uk
- Jacqueline Knibbs, Academic Supervisor: j.knibbs@coventry.ac.uk
- Carolyn Gordon, Academic Supervisor: ab0477@coventry.ac.uk

Thank you for taking the time to read this information.
Rose Brown

Trainee Clinical Psychologist

Consent slip for research study:

I give my consent to be contacted by the Principal Researcher (Rose Brown) about participating in the research study. I understand that taking part in the study is voluntary and that I am able to withdraw from this at any time. This will not affect my support by services in any way.

Name:

Contact details (phone number):

Appendix D. Consent form

(Headed paper)

Consent Form

The experiences of sons and daughters of Shared Lives carers offering family placements to adults under the Shared Lives scheme.

Principal Researcher: Rose Brown

Name: _____

Please read the following information carefully and tick the boxes if you agree.

I have read and understood the information sheet outlining the research study.

☐

I have had the opportunity to ask questions and I feel satisfied that these were responded to.

☐

I understand that taking part in the study is voluntary and that I am able to withdraw from this at any time. I also have the right to withdraw my data from the study up until 1st January 2015. This will not affect my support by services in any way.

☐

I am aware that the interview will be digitally recorded and transcribed. Any personally identifiable Information will be removed from the transcription.

☐

I can confirm that I would like to take part in the research study outlined above.

☐

Name of participant _____ **Signature** _____ **Date** _____

Name of person taking consent _____ **Signature** _____ **Date** _____

Contact Details

If you would like further information about the study, you can contact:

- Rose Brown, Principal Researcher and Trainee Clinical Psychologist:
brownr32@coventry.uni.ac.uk
- Jacqueline Knibbs, Academic Supervisor: j.knibbs@coventry.ac.uk
- Carolyn Gordon, Academic Supervisor: ab0477@coventry.ac.uk

Complaints Procedure

If you are unhappy with any part of the research and wish to make a complaint, you can contact the Clinical Psychology Doctorate Course team on: 02476887806

Are you interested in receiving a summary of the study's results?

Yes

☐

No

☐

If you have answered yes, please provide contact details as to where you would like the results summary to be sent:

Appendix E. Demographics information sheet

(Headed paper)

Demographics Information

Please provide us with some additional information about you. All responses will be confidential and will be used solely for the purposes of the research study.

Gender: **Male** ☐ **Female** ☐

What is your age in years? _____

Ethnic Origin? _____

What is your first language? _____

Thank you for taking the time to complete this form.

Appendix F. Interview schedule

1. I wondered if you could tell me a little bit about your family and who is in it?
2. Can you tell me what you remember about how and when your family first began to support people under the Shared Lives Scheme? Could you tell me about how you felt about this at the time?
3. What expectations, if any, did you have about what it would be like for your family to support someone in your home?
4. I am wondering about what your experiences were like when a client/ service user first began their placement with your family?
5. Can you tell me about what family life was like for you all while you were a part of the Shared Lives Scheme?
6. Can you tell me about whether your experiences changed or evolved over time while your family were supporting someone, or when a new client came into your family home, and if so how?
7. Are you able to describe any difficulties that being part of the Shared Lives Scheme had for you personally?
8. I was wondering whether there were any positive things for you personally about that experience?

Appendix G. Debriefing form

(Headed paper)

The experiences of sons and daughters of Shared Lives carers offering family placements to adults under the Shared Lives scheme.

Summary of Research and Aims

Thank you for taking part in the interview. The interview was designed to better understand your lived experiences of being part of the Shared Lives scheme.

A summary of the research findings will be made available to you upon its completion, please indicate your interest in receiving this summary on the form below. Should you wish you withdraw your data from the research, you are reminded that you are able to do this up until 1st January 2015.

While discussing your experiences, it is possible that we may have talked about sensitive or emotive topics. If you feel that you would benefit from further support related to this, please find a number of services that may be of support to you listed below.

- **Carers UK** are a charity aimed at supporting people who look after family members or friends. You can access advice and support by calling: **0808 808 7777**
- If you are currently a Shared Lives carer, you can also contact [*name removed*], the **Shared Lives Carer Support and Development Worker**, on the following number: [*Telephone number removed*].
- Further support such as counselling and other talking therapies can be accessed via your G.P. should you feel that this would be beneficial.

Contact Details

If you would like further information about the study, you can contact:

- Rose Brown, Principal Researcher and Trainee Clinical Psychologist: brownr32@coventry.uni.ac.uk
- Jacqueline Knibbs, Academic Supervisor: j.knibbs@coventry.ac.uk
- Carolyn Gordon, Academic Supervisor: ab0477@coventry.ac.uk

Thank you for taking part in this study, your time is greatly appreciated.

Rose Brown
Trainee Clinical Psychologist
Universities of Coventry and Warwick.

Are you interested in receiving a summary of the study's results?

Yes

☐

No

☐

If you have answered yes, please provide contact details as to where you would like the results summary to be sent:

Appendix H. Table 2.2 Summary of stages of analysis

Stage	Description of process
Reflection & Transcription	Following each interview reflections were noted in a reflective diary and the interview was transcribed verbatim.
Step 1. Reading and re-reading	This step was characterised by becoming fully immersed and familiar with the data. Listening back to the audio recordings further supported this process.
Step 2. Initial noting & developing emergent themes	Areas of interest within the transcript were commented on from a descriptive, linguistic and conceptual standpoint. Themes were identified and the analysis became more of a collaborative process, of both the lived experiences of the participants and the interpretations of the researcher.
Step 4. Searching for connections across emergent themes	This process involved searching for patterns in the themes that had been identified and grouping them together in terms of the most important aspects of the participant's experiences.
Step 5. Moving to the next case	The next participant's set of data was then analysed and the above process was repeated. As far as possible each data set was treated individually.
Step 6. Looking for patterns across cases	This final step involved constructing a table of themes from each case and drawing out links between them. Checking back with individual interviews was important to ensure they were reflected in the analysis as a whole.

<p>Defining the people who come to Steely messies</p> <p>* <u>Ressies</u> - short for residence. is it a term of endearment? Othering - not family but a collection of 'messies'.</p>							<p>(12)</p> <p>He wanted to move to Australia a need to distance himself & get away from the messies</p>
<p>A need to Disconnect before becoming a man</p> <p>A need to separate.</p>			R	going to go and live out there as well. And er yeah. And. And the residents part of it just sort of sorted itself out really that was just easy you know. It was like an episode of Emmerdale farm.			<p>sorted itself out - secondary to his decisions & life? Separate to him</p> <p>→ didn't feel real? did it feel as though he was acting apart</p>
		24.53	P	Yeah in the farm house!			
<p>Sharing in family events</p>							
<p>Keeping up appearances: participating in family events</p> <p>Do it for the service users</p> <p>Adapting & accepting</p> <p>sadness & loss</p>		25.15	P	<p>So everybody would go at the same time then?</p> <p>Yeah well my mum would always do, she'd always, the residents would have about three holidays, they'd normally have one abroad and then they'd have a couple in this country. Which is pretty much what they do now still. And when I could afford it, when I was around I used to go if I couldn't go on the aboard holiday I'd certainly go on one of the, you know we'd go on one of the holidays. And you know and mum would used to normally pay for us so it was easier that way and yeah it was fine. And again we used to have a bit of banter and the residents used to love it because they were on holiday, they'd go to the club house, play the bingo. Enjoy themselves and um. We used to go sit up there so it was great really was great. And then after a few years we lost Jodie. Jodie became ill with the, again she had quite complex needs with the you know. And she died, I don't know exactly, probably was to do with the, I think it was kidney failure in the end that got her. So we lost Jodie and she. Her funeral was quite sad um.</p>			<p>Sharing in family holidays.</p> <p>Residents: this has changed from 'lads' - does it reflect his distance from them in the past. More formal relationship. Change in her to 'lads' reflects his closeness / informality / comfortable relationship. afford it vs. pay for us</p> <p>maybe it wasn't when he could afford it - perhaps it was more about when I was able since he still needed to separate himself from the family routine.</p> <p>fine: vague term. Not good or bad, just okay.</p> <p>lost - sadness. something missing from their dynamic.</p>
			R	What was that like for you at the time?			Jodie passed away.
		26.29	P	It was quite upsetting that was at the time. That was umm. I'd been to Australia and come back so I'd been gone like a year and half so I'd missed a lot. you know, I missed so much when I come back, It was the first year of Big Brother. And everyone was			<p>missed a lot - did he miss them? missed knowing about day to day life.</p>

A need to disconnect + focus on his own life.

<p>Becoming a man: maturing</p> <p>Rock solid: as service users of the bedrock of the family</p> <p>she was always - what? temporary?</p> <p>could die? - did this influence his choice not to get too close to her? don't get close because she could leave. conditionality</p>				<p>different →</p> <p>- more independent - not like the service users?</p> <p>what? temporary?</p> <p>could die? - did this influence his choice not to get too close to her? don't get close because she could leave. conditionality</p>	<p>talking about Big Brother so it was like. Yeah it was a bit. And I'd I'd gone, I'd matured because I went on my own and I didn't have my mum wiping my backside for me over there suddenly you have to do everything for yourself don't you. I did come back obviously a different person and a lot heavier and er. And yeah her, and then she died not long after I'd come back. I didn't feel any guilt that I didn't see her when I went away because I knew she had an ambulance out to the house every now and again with her diabetes and stuff so I knew she was always she was always. Beryl seemed rock solid and Daniel seemed rock solid as normal as he does to this day. The bloke, I swear the bloke hasn't aged. [laughs]</p> <p>He just doesn't change!</p>	<p>wiping my backside - doing everything for him</p> <p>is this what the service users have? is there a shame in being cared for / dependent?</p> <p>→ maybe separating himself + moving away was a way of shaking himself from this separating his care from his mum to her care for the service users?</p> <p>Something reassuring in people not changing.</p>
<p>Rock solid: can rely on them not to change.</p> <p>All the jokes come out: Humour to manage difficulties</p>	27.3	P		<p>He's just one of them that doesn't change bless him and [pause] yeah they um. So we lost Jodie and the funeral itself was quite sad. Umm. There was some love you know, obviously people, care care you know, caregivers and the day centres that she went to that probably knew her [pause] for the same things really, she was very mischievous. And all the jokes come out at the funeral you know and all that. And it was lovely but it was sad as well.</p>	<p>One of them: them vs us. They feel separate to him + his mum.</p> <p>Jokes: humour as a way of coping with sadness.</p> <p>lots of people cared for her. There is likeability & value in being mischievous.</p>	
		R		<p>I bet yeah. And was that a big change for the family when Jodie died?</p>		
	28.1	P		<p>We moved house, mum, mum moved house, I'd umm. I bought a house, er well I bought this and umm. So I'd gone from, this was pretty much derelict when. We took, the whole house went back to the brickwork so all the plasters come off.</p>	<p>He moved out. Mum also moved house. His house was a big project.</p>	
		R		<p>Aww that's why you've got those lovely bricks?</p>		
<p>Becoming a man separating himself from the family</p>		P		<p>Yeah they were out, yeah so they were out the chimney, this, there was an old, this was two rooms and they were knocked out the old, that's why they're all sooty really. They were knocked out and then rebuilt. Everything's been re-done really. Umm a lot of work, so I lost a lot of time there really and before I knew it</p>	<p>lost a lot of time from the service users' family life?</p> <p>There's a sense that he now new invested in his</p>	

A life of his own.
A need to disconnect + rewire.

<p>The "fit" within the family.</p> <p><u>conditionality</u>: play by the rules to be part of the family</p>	<p>Beryl was asked to leave. This was a hard decision</p>		<p>umm mum was telling me about Beryl doing all these things and she was <u>getting naughty</u> and not doing as she was told and umm. It was like she was getting a bit upset with her saying she'd gone from being the most <u>easiest person</u> to have around and the funniest to. I think it was just her age and her <u>condition</u> really, down's, because she was in her 40's, 50's umm. [pause] then we then I know she was discussing about looking for somewhere else to <u>accommodate</u> Beryl's needs really.</p>	<p>Beryl was asked to leave because her behaviour had changed + become more disruptive. This was a difficult decision. (14)</p>
<p>Conflict in saying goodbye's mum <u>battled</u> with it.</p> <p>Family comes 1st: sacrificing service users for the good of the family</p>	<p>29.3 2</p> <p><u>Battled</u> this was so hard</p> <p>like it was purposeful childhood</p>	<p>P</p>	<p>That was quite upsetting, because she was, it was like. [pause] When you're away from it you don't see it. And I think I used to say "are you sure, are you sure you want to do that? You know, it's Beryl at the end of the day". And mum, I think mum <u>battled</u> with it for a good year. It wasn't like, it wasn't like oh you've done this and you're going. It was a case of, I think umm, it was making mum ill. Because of the arguments, because like you know just er [pause] the <u>naughtiness</u> that was going on with her and stuff and she'd literally just pinch one you know, or someone like, but really, grabbing and, you know, draw blood and stuff and umm. Only ever now and again but it was getting more frequent and umm again I felt a little bit bad with that and <u>guilt for her</u></p>	<p><u>getting naughty</u> - like a child. Treated like a child who must follow rules + not an adult. <u>easiest? compliant?</u> <u>condition</u> - changes attributed to her disability. the family can meet her needs if she is non compliant. if she doesn't fit in there is a need to make her - family comes 1st? <u>Are you sure</u> - he struggled with this decision. it's Beryl - there is something special & different about Beryl. He allowed himself to be close to her - more reluctant for her to leave. <u>making mum ill</u> - families needs come 1st Because he was close to her when you're close there is unconditional love. leaving he feels bad because this wasn't there? Beryl's behaviour was impacting on other service users.</p>
<p><u>part of the family</u>: a close relationship</p>	<p>30.3 1</p>	<p>P</p>	<p>Yeah I think it's just because she'd become part of, <u>part of the family</u>, she was like a big sister really. I used to tell everybody when I was, arr Beryl's my sister, I used to just actually just say that if we was ever out and about because [pause] she <u>pretty much acted</u> like that, if you know what I mean, it was, we were a <u>quite close, a close family</u>.</p>	<p><u>part of the family</u> He would tell people she was his sister + it felt like she was <u>pretty much</u> - sense of not completely? <u>acted</u> - sense that it was something she did that made her seem this way was it the physical closeness?</p>
<p>Becoming a sibling</p>		<p>R</p>	<p>Why do you think it felt different to maybe the other people living with you, Daniel and..</p>	<p><u>Sighs</u> - this is hard to think about - it's complex problem to define his relationship with Daniel or he is frustrated by it?</p>
		<p>P</p>	<p>[sighs] umm Daniel, Daniel kept himself to himself so he'd go off</p>	

No reciprocity in this relationship

Kept himself to himself - distant, private
although there is value in being private; this doesn't

Family grows through familiarity.

A constant part of the furniture

Fond memories: his relationship with Beryl was affectionate & playful. (15)

<p>Affection Joy in playfulness</p> <p>A reciprocal relationship</p> <p>A desire to engage: wanting to be where the action was</p>		<p>little Buddha ↳ a curmish & harmless quality.</p> <p>Reciprocity</p>	<p>on his walks. Beryl wouldn't just leave the house, Beryl was always in the lounge really, and you'd come home and any day, and she wasn't at the centre on the weekends, Saturday and Sunday she was in the lounge legs crossed and sat like a little Buddha, sort of sat their legs crossed, thumbs up smiling. She was lovely and she used to make me laugh and like so you'd walk past and she'd blow a raspberry or something just just just, just yeah just. Umm or she'd throw like a pillow at you or something like that you know, yeah yeah yeah. So you'd pick the pillow up and throw it back and, and there was always something going on with Beryl whereas, Daniel you'd come in and he'd be in his room, you see he loved his room. He had his own TV, his own things, he had phone's on umm he'd be into his own magazines. And he'd he'd he'd come in and he'd just say "oh I'm just off up the shops". And my mum would be like yeah fine, that's fine and umm he'd go off and do his own thing. He'd come back in, you'd see him in brief intervals you see but with Beryl she was never in her room. She was always down where the action was, she was always down as in with the family. → with sense that she tried.</p>	<p>wouldn't/always - dependent on the house & family? a constant.</p> <p>laugh/smiling: value in humour. She is very (if needed) she engaged him in a relationship it was easy to like her compared to Daniel?</p> <p>throw it back - reciprocity</p> <p>This was a two way process; this makes a relationship. He got something out of this relationship</p> <p>Daniel was independent & private - although there is value in this; its hard to know him / feel close</p> <p>is it that she made the effort with the family?</p>
<p>Sharing in milestones + events</p>	<p>32.09</p>	<p>P</p>	<p>So yeah, so you sort of, and we had her, I think, we had her er in fact we had her, she was, I remember having her 40th, so she was in her 40's yeah because we had her 40th and we had a lot of people round, a lot of the care group and I think er, one of the, the CPN, I don't know what she had. A lot of people, her key worker I suppose it would be called, come round and it was quite nice, so they eat cake and that and that was lovely. Umm but then as I say, my, I got taken up with this then you see umm</p>	<p>had her: belonging, ownership</p> <p>having: he had the birthday</p> <p>↳ emphasises her dependency & lack of agency?</p> <p>↳ mentions professions - sense she is dependent on professional's</p> <p>↳ he wasn't as involved</p>
<p>Disconnected & focussed on his own life.</p>		<p>R</p>	<p>With the house? place name</p> <p>With the house. Mum moved to another house in [redacted] it was smaller, when, she didn't take Beryl with her to this house, that's when Beryl found another place, so Beryl went. And she</p>	<p>He was focussed on his own life.</p> <p>Beryl left the house & his mum moved.</p>

Conditionality of being part of the family home.

↳ went: from the family sense of not existing once you leave the family

Appendix J. Guidelines for authors: Journal of Intellectual and Developmental Disability

Journal of Intellectual and Developmental Disability considers all manuscripts on the strict condition that

- the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.
- the manuscript has been submitted only to *Journal of Intellectual and Developmental Disability*; it is not under consideration or peer review or accepted for publication or in press or published elsewhere.
- the manuscript contains nothing that is abusive, defamatory, libellous, obscene, fraudulent, or illegal.

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This journal is compliant with the Research Councils UK OA policy. Please see the licence options and embargo periods [here](#).

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Manuscript submission

Copyright and authors' rights

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Manuscript preparation

1. General guidelines

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- Manuscripts are accepted in English. Macquarie Dictionary spelling and punctuation are preferred. It is Australian convention to use "-ise" endings rather than "-ize" (as in "organise") and "-our" endings rather than "-or" (as in behaviour).

- Please use double quotation marks, except where “a quotation is ‘within’ a quotation”. Long quotations of 40 words or more should be indented without quotation marks.
- The suggested maximum length for each type of submission is: Full-length Articles – 7000 words; Brief Reports and Case Reports – 3000 words; Data Briefs and Opinions & Perspectives – 2000 words. Manuscripts exceeding these limits may be accepted depending on the importance and complexity of the content. Please note that word count includes references, tables, and figures.
- Manuscripts should be compiled in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- Abstracts of 150 words are required for all manuscripts submitted.
- Each manuscript should have 3 to 6 keywords.
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#).
- Section headings should be concise.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.
- Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate paragraph, as follows:
 - *For single agency grants:* "This work was supported by the [Funding Agency] under Grant [number xxxx]."
 - *For multiple agency grants:* "This work was supported by the [Funding Agency 1] under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx]."
- Authors must also incorporate a SI units. Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed equations or image files within their manuscript
- Data Sharing : Authors of data-based articles in JIDD should have their research data available for at least five years after publication. On request, these data should be shared with other competent professionals for reanalysis, solely for the purpose of verifying the published findings, provided that

participants' confidentiality is protected and unless legal rights concerning proprietary data prevent their release. Where relevant, the specific computer program used for data analysis should be identified.

- **Data Briefs** : This section contains succinct summaries of significant current data (often national data) on trends in demographics, service provision, expenditure, and other issues. No abstract is required.
- **Opinions & Perspectives** : This section provides a forum for discussion and debate about important current issues, innovations and policy perspectives in the form of short, well-reasoned, clearly written commentaries. No abstract is required.

2. Style guidelines

[↑Back to top.](#)

- Authors should prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th ed.). Text should be double-spaced.
- [Description of the Journal's reference style.](#)
- [Guide to using mathematical scripts and equations.](#)

3. Figures

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- Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.
- Figures must be saved separate to text. Please do not embed figures in the manuscript file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

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- Authors must ensure that research reported in submitted manuscripts has been conducted in an ethical and responsible manner, in full compliance with all relevant codes of experimentation and legislation. All manuscripts which report in vivo experiments or clinical trials on humans or animals must include a written Statement in the Methods section that such work was conducted with the formal approval of the local human subject or animal care committees, and that clinical trials have been registered as legislation requires.
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7. Supplemental online material

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Authors are encouraged to submit animations, movie files, sound files or any additional information for online publication.

- [Information about supplemental online material](#)

Manuscript submission

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Appendix K. Guidelines for authors: Health & Social Care in the Community

Health & Social Care in the Community

Author Guidelines

1. GENERAL

Health and Social Care in the Community (HSCC) is an international journal with a multidisciplinary audience. Original papers are sought which are empirically grounded and reflect the broad range of practical and theoretical issues underpinning the provision care in the community. The journal publishes:

- Original research papers in all areas of health and social care (data should normally not be more than five years old)
- Topical health and social care review articles
- Policy and practice evaluations
- Special issues

Anyone involved in social work, primary health care and the promotion of health will find HSCC vitally important. Please read the instructions below carefully for details on the submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication in *Health and Social Care in the Community*. Authors are encouraged to visit Wiley-Blackwell [Author Services](#) for further information on the preparation and submission of articles and figures.

2. ETHICAL GUIDELINES

Health and Social Care in the Community adheres to the following ethical guidelines for publication and research. The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

2.1. Authorship and Acknowledgements

Authorship: ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research, the number of authors should not exceed six.

It is a requirement that all authors have been accredited as appropriate upon submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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2.2 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest.

These include financial interests (for example patent, ownership, stock ownership, consultancies, speaker's fee).

HSCC requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflicts of interest noted. As of 1 March 2007, this information will be a requirement for all manuscripts submitted to the Journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of your manuscript.

If the author does not include a conflict of interest statement in the manuscript then the following statement will be included by default: 'No conflicts of interest have been declared'.

Source of Funding: Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

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2.3 Appeal of Decision

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3. SUBMISSION OF MANUSCRIPTS

Manuscripts should be submitted electronically via the online submission site <http://mc.manuscriptcentral.com/hssc>. The use of an online submission and peer review site enables immediate distribution of manuscripts and consequentially speeds up the review process. It also allows authors to track the status of their own manuscripts. Complete instructions for submitting a paper are available online and below. Further assistance can be obtained from the HSCC Editorial Office, by e-mail: HSCCoffice@wiley.com

3.1. Getting Started

1. Launch your web browser (supported browsers include Internet Explorer 6 or higher, Netscape 7.0, 7.1, or 7.2, Safari 1.2.4, or Firefox 1.0.4) and go to the journal's online Submission Site: <http://mc.manuscriptcentral.com/hssc>.
2. Log-in or click the 'Create Account' option if you are a first-time user.
3. If you are creating a new account after clicking on 'Create Account', enter your name and e-mail information and click 'Next'. Your e-mail information is very important. Enter your institution and address information as appropriate, and then click 'Next'. Enter a user ID and password of your choice (we recommend using your e-mail address as your user ID), and then select your area of expertise. Click 'Finish'.
4. If you have an account, but have forgotten your log-in details, go to Password Help on the journals online submission system <http://mc.manuscriptcentral.com/hssc> and enter your e-mail address. The system will send you an automatic user ID and a new temporary password.
5. Log-in and select 'Author Centre'.

3.2. Submitting Your Manuscript

6. After you have logged in, click the 'Submit a Manuscript' link in the menu bar.
7. Enter data and answer questions as appropriate. You may copy and paste directly from your manuscript and you may upload your pre-prepared covering letter.
8. Click the 'Next' button on each screen to save your work and advance to the next screen.
9. You are required to upload your files.
 - Click on the 'Browse' button and locate the file on your computer.
 - Select the designation of each file in the drop-down menu next to the 'Browse' button.
 - When you have selected all files you wish to upload, click the 'Upload Files' button.
10. Review your submission (in HTML and PDF format) before sending to the journal. Click the 'Submit' button when you are finished reviewing.

3.3. Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc/.docx) or Rich Text Format (.rtf) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing. The files will be automatically converted to HTML and PDF on upload and will be used for the review process. The text file must contain the entire manuscript including title page, abstract, bullet points, keywords, text, references, tables, and simple figures, but no embedded high-resolution figures. Figure tags and figure legends for high-resolution figures should be included in the file. Manuscripts should be formatted as described in the Author Guidelines below.

3.4. Blinded Review

All manuscripts submitted to HSCC will be reviewed by two experts in the field. HSCC uses double-blinded review. The names of the reviewers will thus not be disclosed to the author submitting a paper and the name(s) of the author(s) will not be disclosed to the reviewers. To allow double-blinded review, please submit (upload) your main manuscript and title page as separate files. Please upload:

- Your manuscript without title page under the file designation ‘main document’
- Figure files under the file designation ‘figures’
- The title page, Acknowledgements and Conflict of Interest Statement where applicable, should be uploaded under the file designation ‘title page’

All documents uploaded under the file designation ‘title page’ will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

3.5. Suspension of Submission Mid-way in the Submission Process

You may suspend a submission at any phase before clicking the ‘Submit’ button and save it to submit later. The manuscript can then be located under ‘Unsubmitted Manuscripts’ and you can click on ‘Continue Submission’ to continue your submission when you choose to.

3.6. E-mail Confirmation of Submission

After submission you will receive an e-mail to confirm receipt of your manuscript. If you do not receive the confirmation e-mail after 24 hours, please check your e-mail address carefully in the system. If the e-mail address is correct please contact your IT department. The error may be caused by spam filtering software on your e-mail server. Also, the e-mails should be received if the IT department adds our e-mail server (uranus.scholarone.com) to their whitelist.

3.7. Manuscript Status

You can access ScholarOne Manuscripts (formerly known as Manuscript Central) any time to check your ‘Author Centre’ for the status of your manuscript. The journal will inform you by e-mail once a decision has been made.

3.8. Submission of Revised Manuscripts

Revised manuscripts must be uploaded within three months of authors being notified of conditional acceptance pending satisfactory revision. Locate your manuscript under ‘Manuscripts with Decisions’ and click on ‘Submit a Revision’ to submit your revised manuscript. Please remember to delete any old files uploaded when you upload your revised manuscript. Please also remember to upload your manuscript document separate from your title page.

4. MANUSCRIPT TYPES ACCEPTED

Quantitative Articles: Full details of our guidelines for quantitative articles are available at: http://www.blackwellpublishing.com/pdf/hsc_962_rev.pdf. Manuscripts should be compatible with the Uniform Requirements for Manuscripts Submitted to Biomedical Journals (<http://www.icmje.org/>), with randomised intervention studies reported according to CONSORT recommendations (www.consort-statement.org), non-randomised intervention studies to TREND recommendations (www.trend-statement.org), and observational studies to STROBE recommendations (<http://www.strobe-statement.org/>). Other study designs should be reported to a similar structure and standard.

Qualitative Articles: The Journal publishes manuscripts of studies using a range of qualitative designs including grounded theory, ethnography, phenomenology, participatory/action research, case studies and others. Authors are encouraged to provide sufficient detail for reviewers and readers to critique all components of the manuscript. Manuscripts would normally include the headings and content areas as outlined below. Details on the requirements for abstracts are outlined in Section 5.

Introduction: The introduction should include sufficient background including a thorough and integrated review of the literature. The editor acknowledges that in some qualitative research traditions, particularly grounded theory, researchers may prefer to outline the literature quite briefly at the beginning of the research reporting process and discuss the literature in depth in relation to the study findings later in the discussion section of the manuscript. While this is acceptable to some degree, there remains the need to outline sufficient literature at the beginning of the manuscript to provide a scholarly context and rationale for the paper. The literature review should convince the reader that the study was undertaken using established research criteria such as the prevalence of the phenomenon/problem; the importance or impact of the phenomenon/problem in relation to individuals and families; the impact of the phenomenon/problem on health service utilisation (as relevant); etc. Theories or concepts in relation to the phenomenon under study may also be included to provide the theoretical underpinnings of the study. Empirical studies, theoretical papers, policy/government reports would normally be cited. Gaps in the empirical and/or theoretical literature are also noted. It is also important that the literature review be concisely written and well integrated. A clear statement of the purpose/aims of the study should be included in the introduction. This should be consistent with what is written in the abstract.

Methods: Some studies also benefit from the inclusion of a sub-heading which includes background information which specifically orientates the reader to the particular study site or programme. Also, if preliminary work was carried out in preparation for the study, this should be reported with details as to how it informed the main study.

The Methods section would normally include the following:

- type of study design including the rationale for the selection of the particular design with literature support
- data collection methods – include details such as the interviews (or observation approaches or other data collection methods) with rationale and literature support
- data collection procedures including recruitment, settings, sampling, etc.

- the consenting process including how informed consent was secured, who secured the consent, etc.. If written consent was not given, authors need to state how informed consent was secured
- dates of data collection
- analysis procedures with literature support. Include details on any computer software used to manage data (if appropriate)
- discussion of the steps taken to enhance the rigour of the research process and findings
- details of formal research ethics approval
-

Findings: Normally, a description of the characteristics of the participants is included at the beginning of the findings section.

A short overview of the findings (a sentence or two) helps to orientate the reader to the text which follows, i.e. the number of themes and the names of the themes (other terminology is also acceptable). The language used to name the themes should be similar to that reported in the abstract and the more detailed text which follows.

Also, the order of presentation of the themes needs to be the same. This assists the reader to follow the logic and direction of the paper. The data analysis needs to be of sufficient depth to ensure that the findings are presented at a conceptual level. A simple descriptive presentation of the data is not adequate.

It would be expected that qualitative interviews would include excerpts from the data as part of the process of reporting the findings and establishing the credibility of the research process. Excerpts, other than a short sentence within quotation marks in the text, should be single spaced and indented in the text. A colon is used at the end of the text prior to the quoted data excerpt. Authors should include the code number (or facsimile, i.e. pseudonym) in brackets at the end of the quote. When there is more than one category of participants in the study (such as social workers and clients or particular age groups), authors should use an identifier (i.e. SW01 could refer to the first social worker participant; C03 could refer to the third client participant; YA 10 could refer to the tenth young adult participant). Including the participant number and/or participant group helps the reviewer ascertain the range of the sample used to report the findings, which assists in assessing the credibility of the findings.

Occasionally, authors prefer to include quotes in a box or table at the end of the paper. This is acceptable providing the data are well organised and presented.

Discussion: Normally, the discussion should contain an interpretation of the findings and comparisons of the findings from other studies (both similarities and differences). It should also include the authors' critical reflection on the strengths and limitations of the study that may affect the transferability of the findings to other populations such as problems with sampling, recruitment, attrition, deviations from the research protocol or other problems during data collection or data analysis procedures.

Authors should include, where relevant, the implications of the study findings for practice and policy. A brief conclusion should be added to the manuscript that does not merely summarise the findings.

The Journal acknowledges that there may be variations in the interpretation of the presentation of the findings and discussion in qualitative research. Where possible, authors are requested to follow the processes outlined above.

Examples of Published Qualitative Manuscripts:

- Bengtsson-Tops A., Saveman B.I. & Tops D. (2009) Staff experience and understanding of working with abused women suffering from mental illness. *Health and Social Care in the Community* **17**, 459-465.

- Gilbert L. & Walker L. (2010) 'My biggest fear was that people would reject me once they knew my status...': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg. *Health and Social Care in the Community* **18**, 139-146.
- Lee I., Wang H.H., Chiou C.J. & Chang S.H. (2009) Family caregivers' viewpoints towards quality of long-term care services for community-dwelling elders in Taiwan. *Health and Social Care in the Community* **17**, 312-320.

Review Papers: We welcome systematic, narrative and scoping reviews. In addition, we welcome 'state of the art' papers that address issues and topics relevant to health and social care in the community, and appeal to a multidisciplinary and international audience. All review papers are overseen by the Reviews Editor.

We would expect that reviews submitted to the journal are rigorous, robust and up-to-date. The dates the review commenced and finished should be in both Methods and Abstract. Reviews should have a maximum of 7000 words. Authors who submit systematic reviews are expected to follow established guidelines such as those provided by the University of York Centre for Reviews and Dissemination guidance for undertaking systematic reviews in health care (<http://www.york.ac.uk/inst/crd/>).

Authors who submit scoping reviews are expected to follow guidance on scoping reviews such as the methodology guidance by Arksey & O'Malley (2005) (Reference: Arksey H & O'Malley L (2005) Scoping studies: towards a methodological framework, *International Journal of Social Research Methodology*; 8:1: 19-32); or Levac et al (2010) (Reference: Levac D, Colquhoun H, O'Brien KK (2010). Scoping studies: advancing the methodology. *Implementation Science*; 5:69. DOI 10.1186/1748.5908-5-69).

For those authors submitting a descriptive, critical, narrative or scoping review we would expect them to follow the guiding principles of the systematic review process (outlined below) in order to maintain a high standard of review.

Methods used in all reviews should be guided by the key principles of systematic review process (where appropriate). These are:

- Reviews start with clearly formulated topic or research question
- Reviewers strive to locate all relevant literature from a variety of sources and report their search strategies
- Reviews contain explicit study inclusion and exclusion criteria
- All studies are critically appraised
- All studies are examined and judged according to preset quality criteria
- The results of this in-depth analysis are summarised both *within* and *across* studies. Tables/Figures of more than 2 pages will only appear in the online version of the paper
- Conclusions are drawn from a synthesis of the results of included studies
- Overall findings are based on studies which are the most methodologically sound

Authors are encouraged to seek advice from the Reviews Editor if necessary, and consult section 5.6 on Supporting Material.

Policy Papers: Authors should be mindful that HSCC is an international journal and where possible the discussion should draw from international sources.

Special Issues: From time to time the Editor may commission a special issue of the journal which would take the form of a number of papers devoted to a particular theme. Special issue organisers will be expected to produce introductory and concluding discussion sections.

5. MANUSCRIPT FORMAT AND STRUCTURE

5.1. Style

Authors should remember that they are writing for an international multidisciplinary audience. Authors are strongly recommended to consult recent issues of the journal for an idea of topics, content, presentation and general style. The typescript should be double spaced with a wide margin on either side. Articles should not exceed **5000 words** (excluding figures, tables and the reference list).

5.2. Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

Units: Measurements where appropriate must be in SI units. Units, Symbols and Abbreviations (Baron & McKenzie Clarke, Royal Society of Medicine 2008) is a useful guide.

5.3. Structure

All manuscripts submitted to HSCC should include: title page, abstract, keywords, bullet points, text, references, tables and figures.

Title Page: This should contain a concise title of the article, names and qualifications of authors, their affiliations and the full postal address, email and telephone number of an author to whom correspondence can be addressed.

Abstract: This should be **non-structured** and should not exceed **300 words**. Where appropriate authors should cover the following areas: objective; study design; location, setting and dates of data collection; selection and number of participants; interventions, instruments and outcome measures; main findings; and conclusions and implications. The Abstract should be followed by **up to 6** key words, **up to 3** bullet points on “*What is known about this topic*”, and **up to 3** bullet points on “*What this paper adds*”, with a total of no more than **110 words** across all bullet points exclusive of the titles (120 including the titles).

The bullet points should give short, clear summaries on “*What is known about the topic*” and “*What this paper adds*” identifying existing research knowledge and new knowledge respectively in terms of **outcome statements** (what is known/added), not **process statements** (what was done). Authors should report, for instance, a specific outcome such as “experiences of patients and carers in the community did not always concur with guideline recommendations”, NOT the generic process “This qualitative study reports on experiences of patients and carers in the community”. Authors may wish to use the last bullet point under “*What this paper adds*” to summarise implications for practice, policy or research. While we allow up to 110 words across all bullet points, authors should note that shorter statements will have a greater impact and are more likely to attract a reader’s attention. Authors should avoid repeating sentences in the Abstract within the bullet points.

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Main Text: Where possible authors should avoid using abbreviations and footnotes. The use of non-discriminatory language is encouraged and spellings should conform with those used in the *Concise Oxford English Dictionary*.

5.4. References

These should be in the Harvard style. In the text the authors' names should be cited followed by the date of publication, e.g., Smith & Parker (2003). Where there are three or more authors, the first author's name followed by *et al.* should be written in the text, e.g. Luker *et al.* (2004). When references are cited within the manuscript in parentheses, they are listed in chronological order and separated by commas, e.g., (Luker 2000, Beaver & Smith 2005, Jones *et al.* 2008). The reference list should be listed in alphabetical order. Up to seven authors may be included for a reference in the reference list; for references with eight or more authors, the first three authors should be named followed by *et al.* in the reference list. The references should list authors' surnames and initials, date of publication, title of article, name of journal or book, volume number or edition, editors, publisher and place of publication. In the case of an article, page numbers should be included routinely, page numbers from books need only be included when referencing direct quotes or paraphrases. Unpublished work should be cited in the text only. Only references to articles genuinely in press should be included in the reference list.

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We recommend the use of a tool such as [Reference Manager](#) for reference management and formatting.

Reference Manager reference styles can be searched for here:
<http://www.refman.com/support/rmstyles.asp>

5.5. Tables, Figures and Figure Legends

Tables: These should be clearly titled, follow a consistent layout, and be referenced within the text. Wherever possible, they should be self-contained avoiding the need for a reader to cross-reference the text to understand a table. Tables should be submitted one per page, numbered using Arabic numbers, e.g. Table 1, Table 2, etc, with titles listed on a separate page, at the end of the manuscript.

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