UNIVERSITY OF EXETER

Literature Review:

How does having a son or daughter with learning disabilities impact the well-being of ageing parents? A systematic review

Empirical Paper:

Sibling discourses of future planning for individuals with learning disabilities: An exploration of taboo

Submitted by Bronwen Royall, to the University of Exeter

as a thesis for the degree of Doctor of Clinical Psychology, May 2019

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: …………………………………………………………..

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SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

LITERATURE REVIEW

How does having a son or daughter with learning disabilities impact the well-being of ageing parents? A systematic review

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Accessible Summary

- Individuals with learning disabilities are often looked after by their parents as they grow old. It can be more difficult for older parents to care for children with learning disabilities.
- We looked at how caring impacts how healthy older parents are. We looked at how caring impacts how older parents feel. We looked at how caring impacts how often older parents see their friends and family.
- Some older parent caregivers had more physical health difficulties than people who do not care for children with learning disabilities. Some older parent caregivers were a bit more sad and worried. Older parent caregivers had lots of friends, but they did not see their families as much as they would like.
- Professionals need to make sure that older parent caregivers get some support if they need it.

Keywords: learning disabilities, ageing parent caregivers, physical health, psychological functioning, social well-being

Abstract

The life expectancy of individuals with learning disabilities has increased over recent decades, resulting in an increased number of parents continuing to provide care as they enter the stages of older age. Given the demands associated with long-term care provision, alongside the challenges accompanying the ageing process, these parents may represent a particularly vulnerable population. As such, consideration of their well-being is imperative. A systematic review of studies examining the physical, psychological and social

well-being of this parent population was conducted. Four electronic databases were searched, which yielded a total of nine research papers.

Regarding physical health, the review highlighted mixed findings when compared to the general population. General trends demonstrated slightly poorer psychological well-being in the target population, although the majority of studies did not report statistically significant differences. Few studies examined social well-being; however, findings suggest that parents’ friendships and leisure activities primarily emerge in the context of their child with learning disabilities. Limitations of the studies are discussed.

Whilst study findings did not highlight significant concerns, professionals should assess parent caregivers’ well-being and remain aware of the challenges they face. Those who are in the later stages of ageing may present increased vulnerability. Further research into the well-being of ageing parent caregivers is required. Research should focus particularly on these parents’ social well-being and the experiences of fathers.

Introduction

The term learning disability (LD) is defined as a significantly reduced ability to comprehend new or complex information, alongside difficulties managing independently. Impaired functioning must be present prior to adulthood, and have enduring effects on one's developmental trajectory. LD are classified as mild, moderate, severe or profound and, whilst they may occur independently, individuals may also experience additional sensory, physical or communication difficulties (Department of Health, 2001). Reported prevalence rates of LD vary widely; however, estimations (for countries included in this review) range between 2.3-2.9% (Australian Bureau of Statistics, 2012; Larson et al., 2018; Public Health England, 2016). Towards the beginning of the 20th century, individuals with LD were primarily cared for in institutions. However, the process of deinstitutionalisation, the promotion of community integration and reductions in funding for specialist services have resulted in increasing dependence on familial care (Fakhoury & Priebe, 2002; Hubert & Hollins, 2000). Consequently, research examining the well-beingof parents whose children have LD has developed within recent years.

To date, empirical literature pertaining to the well-being of this parent population has focused primarily on psychological functioning. When compared to those of typically developing children (TDC) and broader population norms, multiple studies report higher levels of depression, stress and self-esteem issues in parents whose children have LD (e.g. Aunos, Feldman,& Goupil, 2008; Emerson, Hatton, Llewellyn, Blacker,& Graham, 2006). However, some researchreportsparent caregivers' psychological wellbeingto be comparable to that ofparents with TDC (e.g. McConnell, Savage, Sobsey,& Uditsky, 2015;

Seltzer, Greenberg, Floyd, Pettee,& Hong, 2001). This perhaps reflects positive factors associated with parenting a child with LD, including increased life satisfaction, compassion, self-worth and resilience(Beighton and Wills, 2017; Glidden, 2012; Mangan, 2015). Given the variability in these findings, the relationship between caregiving and parents' psychological well-being is increasingly understood by examining moderating factors, including socioeconomic position (Olsson & Hwang, 2008), LD severity (Emerson, 2003), perceived locus of control (Lloyd & Hastings, 2009) and parental appraisals (Peer & Hillman, 2014).

With regard to physical health, research illustrates poorer health-related quality of life,and an increased prevalence of physical symptomatology (e.g. headaches, gastrointestinal problems and respiratory infections) in parents whose children have LD, compared with population norms (e.g. Aunos et al., 2008; Gallagher & Whiteley, 2013). However, other studies fail to identify differences, demonstrating the physical health of both parent populations to be comparable (e.g. Seltzer et al., 2001). Similarly, contradictory findings are illustrated in research concerning social well-being. Parents whose children have LD describe difficulties establishing social networks, reduced engagement in leisure activities and heightened familial discord, ultimately engendering a sense of social isolation (Dyson, 2010; Johnson, O'Reilly,& Vostanis, 2006; Kishore, 2011). Yet other research reports high levels of parental social engagement and participation (Beighton and Wills, 2017).

The aforementioned well-being literature focuses primarily on parents of younger children, perhaps reflecting the previous poor life expectancies of individuals with LD. However, due to recent medical advancements and improvements in social conditions, individuals with LD are increasingly surviving into older age (Walker & Ward, 2013). As a direct consequence, the numbers of ageing parent caregivers has risen considerably (Seltzer, Floyd, Song, Greenberg,& Hong, 2011). Importantly, in accordance with prominent gerontology studies, the term “ageing” is conceptualised (within this review) as 50 years and above. This conceptualisation further corresponds with typical stages of life-cycle transition.

According to family life-cycle theory (Carter & McGoldbrick, 1989; Chilman, 1968), parents’ early fifties are typically associated with the development of adult-adult relationships with their maturing, less dependent offspring. This transitional process is accompanied by parents regaining their own individualised identities, by means of renegotiating familial dynamics, adjusting to alternative social roles and re-developing personal interests. Furthermore, as parents enter into older age they face a decline in physical and cognitive functioning, often becoming more heavily reliant on their adult offspring. For parents whose children have LD however, this trajectory is likely disrupted. As they transition into later-life, many must contend with the limitations of their own ageing, whilst continuing to manage the care-needs of their child (British Institute Learning Disabilities, 2018) and consider the implications of their ageing on their child’s future.

Given these additional challenges, it is important to consider the well-being of ageing parents, within their own right. Among the caregiving literature more broadly, two competing hypotheses consider the potential effects of long-term care provision. Townsend, Noelker, Deimling and Bass’ (1989) “wear-and-tear model” posits that unrelenting responsibilities reduce caregivers’ well-being over time. Alternatively, the “adaptation model” postulates that increased caregiving experiences strengthen carers’ resources, positively influencing their well-being (Lawton, Moss, Hoffman, & Perkinson, 2000). In accordance with these theoretical models, it is hypothesised that the well-being of ageing parents whose children have LD may be either better, or worse than research focused primarily on that of younger parent caregivers.

With regards to the conceptualisation of well-being, it has long been considered complex and difficult to define (Forgeard, Jayawickreme, Kern, & Seligman, 2011). However following a review of key literature, Dodge et al (2012, p. 230) offer a new definition; “the balance point between an individual’s resource pool and the challenges faced”. The authors focus specifically on physical, psychological and social well-being and, in accordance with this recent conceptualisation, the present literature review attends exclusively to these three particular components when considering the well-being of ageing parent caregivers.

Research question

The present review endeavours to highlight and critically appraise the literature pertaining to the following research question:

- What is the association between having a child with LD and the physical, psychological and social well-being of parents aged 50 years and above?

Method

This review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-2015) guidelines, in an endeavour to enhance rigour and minimise bias (Moher et al., 2015). To ensure the inclusion of pertinent literature, strict inclusion/exclusion criteria (based upon the recommended PICOS framework) were developed (Table 1).

Search terms

A scoping search of relevant literature facilitated the identification of key search terms (Table 2). Given the international variation in terms used to denote LD, multiple search terms were included. In order to capture parents aged 50 years and above, search terms associated with both ageing and older age were used. Finally, a range of terms associated with physical, psychological and social well-being were incorporated.

Table 1
PICOS Inclusion Criteria

	Inclusion	Exclusion
Population	Mothers/ fathers with sons/daughters with LD; Mothers/fathers with sons/daughters with LD, in addition to another developmental disability;	Mothers/fathers with sons/daughters without LD; Mothers/fathers with sons/daughters with a developmental disability in the absence of LD;
	Mothers/fathers aged 50 and above; Study sample contains a sub-set of parents aged 50 or above, which is differentiated within the analysis	Mothers/fathers aged below 50; Study sample contains parents aged 50 or above, yet age is not differentiated within the analysis
Intervention	N/A	N/A
Comparison	N/A	N/A
Outcome	Self-reports and/or objective measures of physical health, mental health, psychosocial functioning, life satisfaction, quality of life, social participation, social engagement, social relationships	Studies focused on spiritual, environmental, occupational and financial well-being. Studies focused on family quality of life
Study Design	Peer-reviewed journal articles; quantitative and qualitative methodologies	Book chapters, editorials, theoretical journal articles, systematic literature reviews, literature reviews, meta-analyses, grey literature
	Studies published in English	Studies not published in English
	Studies published from 1st January 2005	Studies published prior to 1stJanuary 2005

Table 2
Search terms

Key concept	Search terms
Learning Disability	Learning disabilit* OR Learning disabl* OR Developmental* disabilit* OR Developmental* disabl* OR Developmental* impair* OR Intellectual* disabilit* OR Intellectual* disabl* OR Intellectual* impair* OR Mental* disabilit* OR Mental* disabl* OR Mental* handicap* OR Mental* retard* OR Mental* impair* OR autis*
Parent	Parent* OR mother* OR father*
Ageing	Aging OR age* OR old* OR elderly OR old age
Well-being	Wellbeing OR Well being OR Well-being OR Quality of life OR Life satisfaction OR Mental health OR Psychosocial function*

Search strategy

Four key electronic databases (Web of Science, PsycINFO, CINAHL and PubMed) were searched on 5th January 2019. All searches were conducted within the “title” and “abstract” fields, in order to ensure that retrieved literature related to the key concepts defined by the research question. Given the variation in the use of Boolean operators across the chosen databases, search strings were suitably adapted where necessary.

The search included quantitative and qualitative peer-reviewed journal articles, published in English. Grey literature was excluded, as variation in publishing principles generateschallenges in accessing, extracting and reviewing the material. Additionally, guidelines regarding the quality appraisal process of grey literature are currently limited, potentially impacting conclusions drawn(Adams, Smart,& Huff, 2017). Given the release of local and international community integration policies for people with disabilities between 2001-2006 (Department of Health, 2001; United Nations General Assembly, 2006; United States Congress, 2005), the review included articles published from 1st January 2005 up until the search date.

Study selection

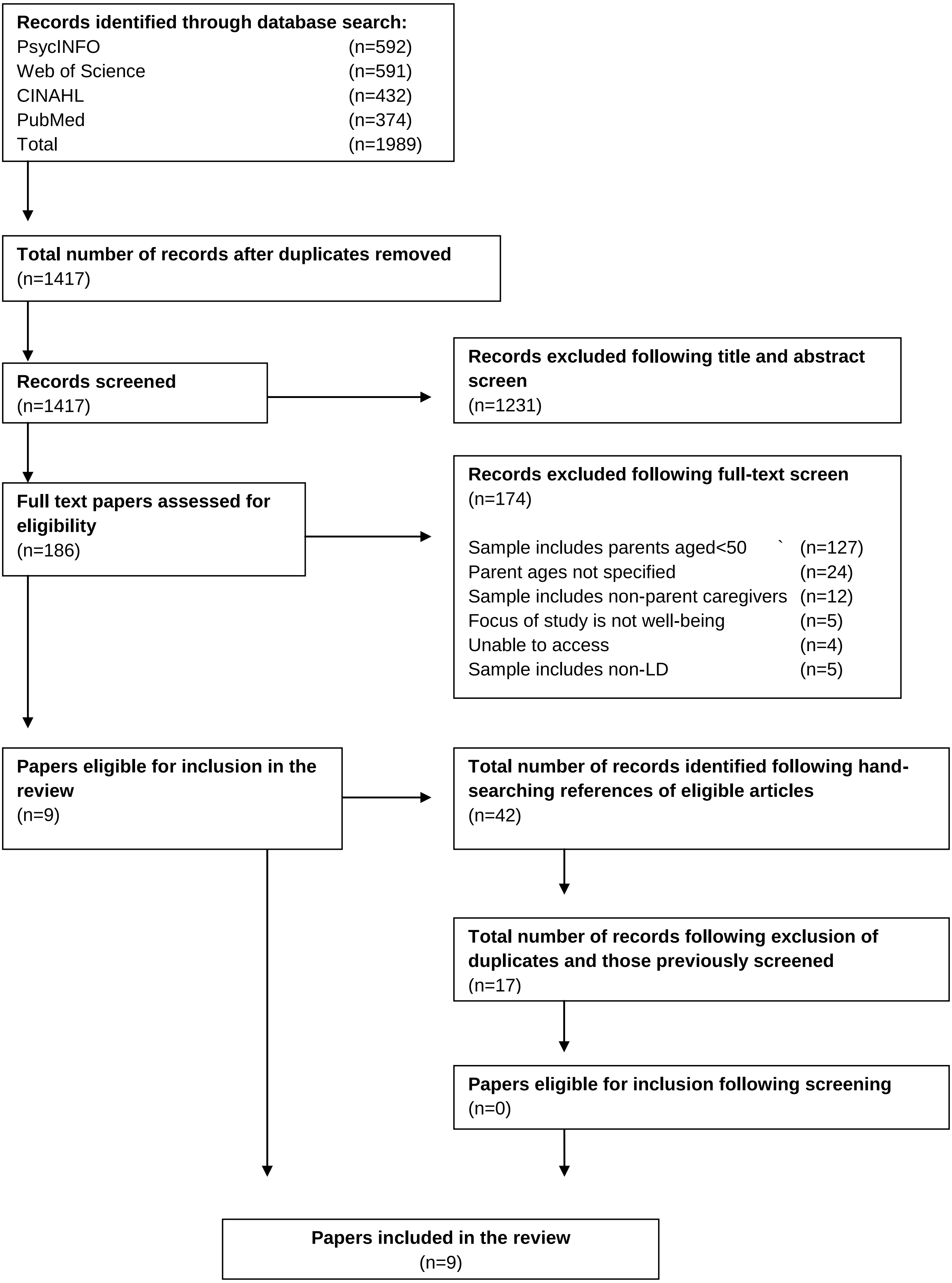
The search yielded a total of 1989 articles, which reduced to 1417 following the removal of duplicates (Figure 1). All articles underwent a preliminary screening process, which involved reading the title and abstract to determine whether they met criteria for inclusion. Consequently, 1231 articles were excluded. The remaining 186 were subsequently subject to a full-text appraisal to further establish their eligibility. Nine articles were identified as fulfilling all inclusion criteria. To identify additional papers not captured by the electronic database search, the reference lists of all included articles were hand-searched. This process yielded a total of 17 articles (following the removal of those previously screened). These articles underwent the aforementioned screening procedures; however, none were identified as eligible for inclusion. Overall, the search yielded a total of nine eligible articles.

To enhance the reliability of selection, six articles were reviewed at the full-text screening stage by an independent second-rater (Moher et al., 2015). The measured Cohen's Kappa for the two ratings was 1.0, indicating complete agreement (McHugh, 2012).

Evaluation Criteria

All included articles were critically appraised to assess study quality. Two standardised appraisal tools were used: (1) the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018), and (2) the Quality Assessment Tool for quantitative studies (Effective Public Health Practice Project, 1998). To enhance reliability of this appraisal process, three articles were evaluated by an independent second-rater. The measured Cohen's Kappa for the two ratings was 1.0, indicating complete agreement (McHugh, 2012).

Figure 1.*Flow diagram detailing search procedure*



Results

Study characteristics, findings and critical appraisal of the nine included papers are summarised in Table 3. Two papers present findings from a longitudinal study at differing time-points (Carr, 2005; Carr, 2008). A further two papers use the same data; however, explore separate research questions (Perkins & Haley, 2010; Perkins & Haley, 2013). Therefore, nine papers derived from seven studies are examined.

Table 3

Summary of articles included in the present review

Author(s)	Aim(s)	Study Design	Country	Target Population	Relevant measures	Relevant Findings	Limitations	Quality rating
Study 1: Cairns et al. (2014)	The study outlined two primary research aims: (1) to explore the experiences of prolonged caregiving on older parent carers and (2) "to examine the effects of prolonged caregiving on self-reported physical and mental health of older parent carers".	Cross-sectional	United Kingdom	Seventy two mothers and 28 fathers (aged 65+) of individuals with mild/moderate (40) or severe/profound (65) LD. Parents were recruited from LD support services and social work agencies across 3 Scottish local authorities.	Physical and mental health was measured using the 36-item self-report General Health Survey questionnaire (SF-36; Ware et al., 2002). Parents also completed several open-ended questions pertaining to their experiences of caregiving.	64% of parents perceived caregiving to have negatively impacted their overall health. Parents aged 75-84 years were significantly more likely to report a negative impact, compared with those of a younger age. On a measure of global physical health, parents aged 65-74 years scored similar to/above UK norms, whilst those aged 85+ scored below UK norms. All age-groups scored below UK norms on the measure of global mental health. Regarding social functioning, parents aged 85+ scored below UK norms.	Cross-sectional study design. Convenience sample. Small sample size. Sample consists primarily of mothers Normative data not representative of study sample. Well-being assessed using self-report measures. Open-ended questions not analysed in accordance with a qualitative methodology. Effect sizes not reported.	**A** Weak **B** Weak **C** Weak **D** Weak **E** Strong **F** N/A **Global:** Weak
Study 2: Carr (2005)	The study aimed to explore the physical, psychological and social well-being of parents and siblings of individuals, aged 30-35, with Down syndrome.	Cohort analytic/ cross-sectional	United Kingdom	Twenty one mothers of individuals with Down syndrome aged 35. Mothers aged 53-82. The sample consists of a cohort of mothers living within a defined	Psychological well-being was measured using the 24-item self-report Malaise Inventory (Rutter, 1970). A guided interview	Mother carers and controls rated their health as "good" (64%; 65%). Mother carers reported less serious illness (43%; 50%). Mother carers reported	Small sample size. Well-being assessed using self-report measures. Fathers' well-being based on	**A** Moderate **B** Moderate **C** Moderate **D** Weak

				geographical region of the UK, who gave birth between 1963 and 1964.	schedule gathered information on social well-being. The interview compiled items from the guided interview schedule for mothers of cerebral palsied children (Hewett, 1970) and the Handicaps, Behaviour and Skills Schedule (Wing, 1980).	greater psychological distress; however, this finding did not reach significance. Increased dependency of offspring was associated with greater distress.15% of mother carers reported loneliness and a greater proportion reported larger social networks compared to controls (70%; 53%). Mother carers reported less familial contact and reduced social participation; however, these findings just failed to reach significance.	mothers' reports. Details of statistical analyses are not provided. The study makes few comparisons with findings from previous time-points and there is variation in the use of measures at different stages, rendering it difficult to make longitudinal comparisons. Effect sizes not reported.	**E** Strong **F** Moderate **Global:** Moderate
Study 3: Carr (2008)	The study aimed to explore the physical, psychological and social well-being of parents and siblings of individuals, aged 40, with Down syndrome.	Cohort analytic/ cross-sectional	United Kingdom	Eighteen mothers of individuals with Down syndrome aged 40. Mothers aged 59-87. The sample consists of a cohort of mothers living within a defined geographical region of the UK, who gave birth between 1963 and 1964.	Psychological well-being was measured using the 24-item self-report Malaise Inventory (Rutter, 1970). A guided interview schedule also gathered information on social well-being. The interview compiled items from the guided interview schedule for mothers of cerebral palsied children	More mother carers rated their health as "good", compared with controls (67%; 50%) and fewer reported to feel "run down" and "depressed". Significant relationship found between poor physical health and child unable to go out unaccompanied. Mother carers and controls reported similar levels of psychological distress, which were both below clinical cut-off and	Small sample size. Well-being assessed using self-report measures. Fathers' well-being based on mothers' reports. Details of statistical analyses are not provided. Effect sizes not reported.	**A** Moderate **B** Moderate **C** Weak **D** Weak **E** Strong **F** Weak **Global:** Weak

					(Hewett, 1970) and the Handicaps, Behaviour and Skills Schedule (Wing, 1980).	population norms. Compared to previous time-points, psychological distress was lower for mother carers. Distress was associated with offspring's' increased dependency, mothers' increased age and smaller social networks. Mother carers reported less social participation; however, this finding failed to reach significance.		
Study 4: Llewellyn et al. (2010)	The study outlined three objectives: (1) "to assess older Australian parent-carer's self-reported health status in comparison to their peers", (2) "to examine the relationship between parent-carer health status, age, gender, care-load and social support", and (3) "to investigate variation in perceived stressors and coping strategies in older parent-carers".	Cross-sectional	Australia	Sixty four parents of individuals with LD (approximately 75% mothers). Parents aged 52-90. The sample was drawn from disability and aged-care support services across northern Sydney, in addition to advertisements in local media. Parents' offspring aged 21-74. 58% had physical difficulties in addition to their LD. 48% lived with their parent(s).	Physical and mental health was measured using the 12-item self-report General Health Survey Questionnaire Short Form (SF-12; Ware, Snow, Kosinski,& Gandek, 1993). The 30-item Carers Assessment of Difficulties Index (CADI; Nolan, Grant & Keady, 1998) assessed self-reported difficulties and stressors associated with caregiving.	Comparisons of parent-carers to their age-peers demonstrated significant differences in mental health scores for the youngest age-group (55-64 years). No other significant differences were found on either the global physical or mental health dimensions. Increasing age was demonstrated to be associated with poorer physical health and enhanced mental health. Increased care-load and smaller social networks were significantly associated	Cross-sectional study design. Convenience sample. Small sample size. Sample comprised primarily of mothers. Well-being assessed using self-report measures. Effect sizes not reported.	**A** Moderate **B** Weak **C** Moderate **D** Weak **E** Strong **F** N/A **Global:** Weak

						with increased psychological distress. Parents with partners reported better physical health, when compared with single parents. More parents (55-64 years) reported increased stress.		
Study 5: Minnes, Woodford & Passey (2007)	The study aimed to address various relationships between factors in the ABCX model. More specifically, it examined whether resources and carer appraisals mediated the relationships between stressors (maladaptive behaviour and carer health), depression and quality of life.	Cross-sectional	Canada	Seventy one mothers and nine fathers (aged 50-88) of individuals with LD. The sample was drawn from disability services across south-eastern and central Ontario, Canada. Parents' offspring were aged 17-59. Their level of disability ranged between mild (27%), moderate (58%) and severe (15%).	Overall health and quality of life were measured usingsingle global ratings. Depression symptomatology was measured using the Centre for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977). Stress associated with caregiving was measured using the 24-item Family Stress and Coping Interview (FSCI; Nachshen et al., 2002).	71% of parents rated their overall health positively. 47% reported feeling satisfied with their quality of life. On average, parents scored within the normal range on a measure of depression; however, 16% obtained scores above clinical cut-off. Depression was significantly correlated with perceived overall health (*r*=.45), perceived ageing (*r*=.49) and perceived stress (*r*=.41). Quality of life was significantly correlated with perceived overall health (*r*=.40), social support (*r*=.40), perceived ageing (*r*=.42) and depression (*r*=.54). Parental appraisals of ageing and caregiving stress mediated the	Cross-sectional study design. Convenience sample. Small sample size. Use of single-item measures. Well-being assessed using self-report measures. Lack of consensus regarding the definitions of various components in the ABCX model, resulting in the use of different instruments as measures of each component.	**A** Moderate **B** Weak **C** Moderate **D** Weak **E** Strong **F** N/A **Global:** Weak

						relationship between carer health and depression. Parental appraisals of stress mediated the relationship between maladaptive behaviour and depression.		
Study 6: Perkins & Haley (2010)	The study outlined two primary aims: (1) to examine the frequency of compound caregiving in a sample of older parents caring for offspring with LD and (2) to investigate whether compound caregivers differ in a variety of quality of life outcomes, alongside the desire to place their offspring into an alternative residential facility.	Cross-sectional	United States of America	Ninety one parents (91% = mothers) of individuals with LD. Parents aged 50-92. 37% of parents identified as compound caregivers. The sample was drawn from support services across Florida, USA, alongside electronic mailing lists, websites and parent-to-parent referral. Parents' offspring aged 18-54. Their level of disability ranged between mild (27), moderate (44), severe (12) and profound (8).	Physical and mental health was measured using the 36-item self-report General Health Survey Questionnaire (SF-36). Depression symptomatology was measured using the CES-D. Life satisfaction was assessed using the 13-item short-form Life Satisfaction Index–Z (Wood, Wylie,& Schaefor, 1969).	No differences between global physical and mental healthwere reported between groups. All were below US norms. Mean scores for depression did not meet clinical cut-off for either group. No significant differences were found between compound and non-compound caregivers on measures of health-related quality of life, depression or life satisfaction. Compound caregivers were significantly more likely to seek alternative arrangements for their son/daughter. Cohen's *d* was 0.67 indicating a moderately large effect (Cohen, 1988).	Cross-sectional study design. Convenience sample. Small sample size. Parent-to-parent referral. Well-being assessed using self-report measures	**A** Moderate **B** Weak **C** Strong **D** Moderate **E** Strong **F** N/A **Global:** Moderate

Study 7: Perkins &Haley (2013)	The study outlined four aims: (1) to investigate whether ageing parent caregivers perceived tangible and emotional reciprocity within their relationship, (2) to explore the relationship between reciprocity and quality of life, (3) to explore the relationship between reciprocity and offspring living arrangementaccommodation and (4) to examine the predictive utility of reciprocity, in accordance with the stress-process model.	Cross-sectional	United States of America	Ninety one parents (91% = mothers) of individuals with LD. Parents aged 50-92. The sample was drawn from support services across Florida, USA, alongside electronic mailing lists, websites and parent-to-parent referral. Parents' offspring aged 18-54. Their level of disability ranged between mild (27), moderate (44), severe (12) and profound (8).	Tangible and emotional reciprocity was measured using a 12-item questionnaire designed by the authors. Physical and mental health was measured using the General Health Survey questionnaire (SF-36). Depression symptomatology was measured using the CES-D. Life satisfaction was assessed using the 13-item short-form Life Satisfaction Index – Z.	Parents reported poorer physical and mental health compared to US norms. On average parents did not meet clinical cut-off for depression. Greater disadvantage in tangible reciprocity was associated with increased depressive symptomatology (r=.29), poorer mental health (r=.24) and a reduced desire to place offspring in alternative accommodation (r=.23). According to Cohen (1988) these values indicate small to medium effect sizes.Emotional reciprocity was not significantly associated with any measured outcomes.	Cross-sectional study design. Convenience sample. Small sample size. Well-being assessed using self-report measures. Measure of reciprocity developed by the researchers for purpose of study – not validated.	**A** Moderate **B** Weak **C** Strong **D** Weak **E** Strong **F** N/A **Global:** Weak
Study 8: Rimmer-man et al. (2018)	The study outlined 3 primary aims: (1) to examine the personal and social lives of ageing mothers of adult children with LD, (2) to compare the lives of single ageing mothers and those in relationships and, (3) to compare the lives of ageing mothers living with and	Cross-sectional	Israel	One hundred and sixty mothers (aged 60+) of individuals with moderate LD. The sample was drawn from sheltered LD employment workshops in central Israel. 93 of the mothers co-resided	Social engagement was measured using the 10-item self-report Lubben Social Network Scale (LSNS; Lubben, 1988). Psychological well-being was measured using the	Mothers demonstrated low psychological well-being. No significant differences were found between single mothers and those in a relationship. No significant differences were found between mothers co-residing	Cross-sectional study design. Convenience sample. Demographic information is limited for mothers and not provided for care-recipient. Measures were	**A** Weak **B** Weak **C** Weak **D** Weak **E** Weak **F** N/A **Global:** Weak

	without their offspring			with their offspring, whilst 67 reported them to live separately.	10-item self-report Affect Balance Scale (Bradburn, 1969). Both measures were translated into Hebrew.	with/without their offspring Mothers scored low on social engagement. Single mothers co-residing with their adult offspring reported significantly increased levels of familial engagement.	translated into Hebrew - not validated. Effect sizes not reported.	
Study 9: Yoong & Koritsas (2012)	The study aimed “to explore the impact of caring for an adult with LD on the quality of life of parents”	Qualitative design Individual interviews. analysed by thematic analysis	Australia	Ten mothers and two fathers (aged 55-77) of individuals with LD. Sample was drawn from disability services in Victoria, Australia. Individuals with LD were described as having low (11) and high (1) support needs.	Semi-structured interview schedule, which was developed following a review of relevant literature and consultation between the authors	Parents described their caregiving responsibilities as providing a sense of purpose, contentment and satisfaction; however, also reported them to restrict their ability to work, generate financial insecurity and engender anxiety. Parents described increased social networks and enhanced levels of social participation due to involvement with support groups. Difficulties in familial relationships and restricted leisure activities were described.	Convenience sample. Sample comprised primarily of mothers. Relationship between researcher and participants not considered, rendering the reader unaware of potential bias. Respondent validation not considered.	CASP score: **7/10**

Study Aims

All studies examined parents' general psychological well-being (1-9); however, three additionally examined depressive symptomology (5, 6 & 7). Studies explored relationships between psychological functioning and confounding/mediating factors, including age, gender, care-load, carer resources, caregiving appraisals, social/family support, reciprocity, caregiver status and living arrangements (1, 4, 5, 6, 7 & 8). Seven studies examined physical health (1-7), four of which explored relationships with aforementioned confounders (1, 4, 6 & 7). Four studies explored social functioning (1, 2, 3 & 8), primarily examining relationships (2, 3 & 8) and participation (2&3). The qualitative study (9) explored parents' quality of life, with analysis generating themes relating to psychological and social well-being.

Study Sample

A total of 528 parents participated across all studies. 89% of participants (six studies) were mothers. The additional study did not report gender statistics (4). Parent ages ranged from 50-92 years across five studies; however, the remainder merely reported that participants were aged above 60 (8) and 65 (1). LD severity ranged from mild to profound. Three studies detailed the frequency of differing severities. Two identified moderate LD as most prevalent (5 & 6/7), whilst the third reported a greater proportion of severe/profound LD (1). Across four studies, the ages of offspring ranged 18-74. Age-range was not specified in the remaining studies (1, 8& 9).

Study Design

Six studies adopted a cross-sectional design (1, 4, 5, 6, 7 & 8), in which self-report questionnaires were completed at a single time-point. Two papers were derived from a prospective cohort longitudinal study, examining a sample of parents at separate time-points (2&3). This study utilised control groups to draw comparisons with parents of TDC, whilst others made comparisons using population norms (1, 4, 5, 6&7). The qualitative study conducted semi-structured interviews, analysed using thematic analysis (9).

Key measures

General Health Survey Short Form Questionnaire (SF-36). Two studies incorporated the SF-36 measure (1 &6/7), whilst one study used a short-form version (SF-12; 4). The 36-item self-report questionnaire assesses eight heath-related domains: physical functioning, pain, physical health limitations, psychological distress, mental health limitations, vitality, social functioning and general health. The measure produces two summary scores for global physical health (PCS) and global mental health (MCS). Higher scores indicate less disability. The measure is widely validated (Theofilou, 2013), with normative data available for multiple populations (e.g. Burholt & Nash, 2011).

Centre for Epidemiological Studies-Depression Scale (CES-D). Two studies used the CES-D (5 & 6/7). The 20-item self-report questionnaire measures depressive symptoms across six sub-scales: depressed mood, worthlessness, hopelessness, appetite loss, sleep disturbance and psychomotor difficulties (Radloff, 1977). Responses are indicated on a four-point likert scale. Scores range between 0-60, with higher scores indicating greater symptomatology. A score of 16 or greater indicates risk for clinical depression. The measure has been widely validated for use in older adult populations (Mohebbi et al., 2018; Radloff & Teri, 1986). It has shown mixed results for sensitivity and specificity (Roman & Callen, 2008), demonstrating, in particular, less sensitivity in identifying mild depression (Lyness et al., 1997).

Malaise Inventory. The longitudinal study used the Malaise Inventory (2/3). The 24-item self-report questionnaire assesses emotional and somatic symptoms associated with psychological distress (Rutter, 1970). Scores range between 0-24, with higher scores indicating increased distress. The measure has demonstrated acceptable internal consistency ranging 0.7-0.8 (Rodgers, Pickles, Power, Collishaw, & Maughan, 1999). Whilst it has been validated for use with mothers of disabled children, it has not been specifically validated for ageing populations (Rodgers et al., 1999).

Relevant findings

Physical health. Studies presented mixed findings with regard to physical health of target parents. One reported their physical health to be over 0.5 of a standard deviation below US norms (6/7), and another found those aged above 85 to report poorer global physical health when compared with normative data (1). This same study found parents (aged 65-84) to score below UK norms on the pain, physical health limitations and general health sub-scales of the SF-36; however, high physical functioning raised PCS scores to that similar of UK norms (1).

Conversely, two studies (2&4) indicated little difference between target parents and control/normative data, whilst one reported a greater proportion of mother caregivers to rate their health as “good” (3). Additionally, one study reported 71% of target parents to rate their physical health positively (5). In examining confounding variables, increased offspring dependency (3), increasing age (1 & 4) and single-parent status (4) were found to be associated with poorer physical health.

Psychological functioning. Five quantitative papers reported poorer psychological functioning in ageing parents of children with LD, when compared with normative data/controls (1, 2, 4, 6& 7). Of these studies, only one reported a statistically significant difference in a sub-group of parents aged 55-64 (4). Despite one study detailing considerable differences between target parents and populations norms (1), statistical significance was not reported (possibly due to small sample sizes). Additionally, one study found high levels of psychological distress in target parents; however, no comparison data was provided (8). All the studies which assessed depressive symptoms produced similar findings, with mean scores ranging 10.2-12.6. These scores are below clinical cut-off, demonstrating that on average target parents did not display particular risk for clinical depression. However, scores were variable indicating that a proportion of participants did meet clinical threshold. Only one study (5) reportedthe number of participants exceeding threshold (16%), which corresponds with national prevalence data (Canadian Psychological Association, 2015).

Factors shown to negatively impact ageing parent caregivers' psychological well-being included increased care-load (2, 4), limited support (3&4) and greater disadvantage in tangible reciprocity (7). Parental appraisals (of ageing and caregiving stress) were identified as mediating the relationship between carer health and depression, whilst appraisals of stress mediated the relationship between maladaptive behaviour and depression (5). Compound caregiving status was not found to be associated with increased levels of psychological distress (6). However, a statistically significant association was illustrated between compound caregiving and the desire to place offspring in alternative accommodation, possibly indicating anticipated/increasing levels of stress in this group of parents. Three studies observed a relationship between increasing age and enhanced psychological functioning (1, 2 &4); however, only one reported this relationship to be significant (4). Additionally, the longitudinal study reported parental psychological distress to be lowest when their offspring were aged 40, compared to all previous time-points (since offspring were aged 11).

Regarding the qualitative study findings, the quality of life of ageing parents of children with LD was described as enhanced by an increased sense of purpose, achievement and contentment. However, they also highlighted heightened levels of anxiety due to financial difficulties, lack of services and future concerns. The nature of these anxieties suggests that situational factors play a role in these parents' psychological functioning.

Social well-being. Three papers explored target parents' level of social participation (2, 3 & 9). The two articles reporting outcomes in the longitudinal research demonstrated that, at both time-points, mothers participated in fewer social activities compared with controls. However, this trend failed to reach statistical significance. Qualitative findings further illustrated that parents engaged less with leisure activities typical for their age-group, yet frequently participated in activities associated with their adult offspring (9).

Regarding social engagement, a greater proportion of target parents reported having "many friends" when compared with controls, and few (15%)

reported loneliness (2). These findings were supported by the qualitative study (9). Though parents' friendship groups were generally restricted to relationships with parents of disabled children, their involvement with support groups had enabled the development of meaningful friendships, and enhanced a sense of belonging. Despite few concerns regarding friendship networks, target parents reported reduced quality time with partners and wider family systems (2&9). However, these findings did not reach statistical significance. Finally, on examining differences in marital status and living arrangements (8), single mothers co-residing with their offspring were found to report greater familial engagement.

Despite largely positive findings, two studies reported low social well-being in ageing parents (1&8). Of note, one only reported below average findings in a sub-sample of parents aged above 85 years (1).For both studies, findings were reported via a single statistic, rendering unclear which aspects of social well-being were examined specifically.

Quality Appraisal

Six of the eight quantitative studies were rated as weak following quality appraisal (1, 3, 4, 5, 7 & 8). The remaining two were rated moderate (2&6) and the qualitative study (9) was rated relatively highly (7/10). This section endeavours to highlight factors which impacted the quality of the studies.

Six studies recruited participants through specialist support organisations, resulting in an element of selection bias (1, 5, 6, 7, 8 & 9). Parents without access to service support were likely largely underrepresented. Considering the support that LD services provide (Walsh et al., 2001), the well-being of parents without support is likely to be lower. Therefore, caution must be exercised when considering the generalisability of findings to all ageing parents whose children have LD.

The quality of six studies was further weakened by their use of a cross-sectional study design (1, 4, 5, 6, 7 & 8). Whilst relatively inexpensive and straightforward to conduct, these studies are prone to certain biases. As they are conducted at a single time-point, cross-sectional studies are unable to infer causality (Setia, 2016). Whilst two papers were based upon a longitudinal study design (2 & 3), they made minimal reference to findings from previous time-points and, as such, could be considered representative of a cross-sectional design when read separately. Additionally, the sample sizes across all studies were small, reducing statistical power and increasing the likelihood of Type II errors (Faber & Fonseca, 2014). For studies differentiating their sample into separate groups to examine within-group variance, this posed an even greater problem.

Limitations regarding certain measures must also be noted. Several studies (2, 3 & 5) used self-reported global ratings to measure certain concepts (e.g. physical health) which, according to classic measurement theory, are not considered as stable or reliable as multi-item measures (Bowling, 2005). Whilst some studies used poorly validated measures (2, 3 & 8), many included measures with good psychometric properties (1, 4, 5, 6, & 7). The use of these measures was a particular strength when assessing study quality.

The quality of the qualitative study was primarily weakened by the failure to acknowledge the relationship between researchers and participants. This prevented consideration of potential researcher bias during study design, data collection and analysis process. Additionally, the study made no reference to respondent validation, potentially impacting the validity of findings.

Discussion

The following section endeavours to outline, discuss within the context of wider literature and critically appraise the main findings generated by this systematic literature review.

Critical Appraisal

Physical health. This review highlights conflicting findings with regard to the physical health of ageing parent caregivers, when compared to controls/population norms. Such discrepancy corresponds with wider literature examining ageing parents of children with a broader range of developmental disabilities (e.g. Magaña & Smith, 2006; Seltzer, Greenberg, Floyd,& Hong, 2004). Several possible explanations may account for these contradictory findings. Firstly, the age-range of parents in the reviewed papers varied widely, with few studies differentiating more specific age-groups. A recent longitudinal study demonstrated that when compared to age-matched controls, parents aged over 65 (whose children had developmental disabilities) exhibited poorer physical ill-heath. However, during their 50's, parents' health was comparable to that of controls (Namkung et al., 2018). The growing disparity in physical health, as caregivers and controls progress into older age,offers support for the "wear and tear" model. Indeed, it may reflect unrelenting demands rendering parent caregivers unable to "slow down" and adjust to normal age-related decline, ultimately provoking additional health difficulties. As such, present conflicting findings may reflect the incorporation of parents prior, and subsequent to this possible divergence.

In addition to the diverse age-range, conflicting findings may be explained by potential differences in levels of parental care.Indeed, general trends in the caregiving literature indicate significant decline in caregivers' physical healthwhen weekly care provision exceeds 50 hours (Carers UK, 2004). Whilst several studies controlled for care-load, only one outlined a significant relationship with poorer physical health. However, none of these studies reported, specifically, the number of weekly care hours provided by parents. Instead, this variable was predominantly measured by children's maladaptive behaviours and functional abilities, which do not necessarily reflect the amount of care-time provided by parents. Indeed, studies included children in supported accommodation and those attending day-centre services, which alleviate demands placed on parent caregivers. Given the failure to appropriately control for all factors associated with care-load (e.g. weekly care hours, living arrangements), the lack of association between this variable and parental physical health should be interpreted with caution.

The complex relationship between caregiving and physical health may also explain the contradictory findings. Whilst several studies examined confounding variables (e.g. maladaptive behaviour and social support), previously shown as impacting caregivers' physical functioning (e.g. Eisenhower, Baker,& Blacher, 2009), Gallagher (2014) suggests that physical health is best understood by considering the interaction of certain variables, rather than by single factors. As such, further research into interactional effects may support the understanding of parental physical health. The complexity of this relationship offers some suggestion as to the competing hypotheses posited by the “wear-and-tear” and “adaption” models of caregiving. Indeed, it is clear that the association between ongoing caregiving and health is not a simple, linear relationship, but one which is mediated by multiple interacting variables. As such, additional research may support the development of a more comprehensive model.

Finally, it is important to acknowledge that reports of good health may have been influenced by the studies predominantly using self-selecting samples. Indeed, parents in better health may have been more willing and/or able to participate in studies. Furthermore, the results may represent a social desirability bias, with target parents reluctant to express ill-heath for fear of being perceived as unfit to continue providing care (Carers Trust, 2015).

Psychological well-being. Target parents exhibited slightly poorer psychological functioning compared with the general population. Specifically, those with limited support networks, highly dependent children and who negatively appraised their level of stress were shown to be particularly vulnerable. However, despite the majority of studies illustrating trends in this direction, only one study reported a statistically significant difference. Whilst these data trends correspond with literature examining ageing parents of children with a range of developmental disabilities (e.g. Seltzer et al., 2011), this wider literature reports larger differences between target parents and controls. Additionally, the impact of caregiving on the psychological functioning of ageing parents whose children have LD, appears less significant than research which has examined younger parent caregivers (e.g. .g. Aunos et al., 2008; Emerson et al., 2006). The present findings therefore provide support for the “adaption” hypothesis (Lawton et al., 2000), which suggests that parents’ abilities to manage caregiving demands increase, thereby alleviating psychological distress over time.

In addition to this notion of adaption, previous research demonstrates that as they age, parents of children with disabilities can become dependent upon their offspring for companionship and support (Bibby, 2013).As such, the well-being of ageing parent caregivers may benefit from a continued caregiving status. This suggestion accords with present findings of a relationship between increased tangible reciprocity and enhanced psychological well-being. Conversely, it was not supported by one paper, which failed to identify differences in psychological distress when comparing parents living with, and without their offspring. However, it is important to acknowledge that this study did not specify the age-range of participants. Given that parents in the latter stages of late-life are more reliant on their children for support (Benbow et al., 1990), the ages of participants may have had a bearing on the findings.

Whilst psychological functioning of ageing parent caregivers did not significantly differ from comparative data (except in one instance), several studies did report larger differences than others (some just failing to reach significance). In those which reported larger differences, demographic data illustrated high proportions of “severe/profound” disabilities, alongside an increased prevalence of additional physical difficulties in parents’ offspring. This suggests that parents in these samples may have had additional challenges to contend with, ultimately provoking higher levels of distress.

Importantly, differences in LD diagnosis, severity and co-morbid conditions may be associated with the variation in findings outlined in this review, more widely. In a similar vein, the age of parents' children varied widely across the studies. Research indicates that LD are associated with premature age-related change and the development of serious health conditions (Esbensen, 2010; Haley & Perkins, 2004). As such, some caregivers would likely have had additional medical difficulties to contend with. Given that the studies largely neglected to consider and control for these variables, these suggestions are highly tentative. However, wider literature indicates these factors to impact caregiver well-being (Olsson & Hwang, 2001) and, as such, further research may be beneficial.

Despite slightly poorer psychological well-being in target parents, data trends highlight a relationship between enhanced psychological functioning and increasing age. These findings correspond with wider gerontology literature, which demonstrates a linear relationship after the age of 50 years (Lorem, Schirmer, Wang,& Emaus, 2017; Stone et al., 2010; Thomas et al., 2016).These findings may therefore merely reflect a universal trend; however, they may also offer additional support to the "adaption model" (Lawton et al., 2000). Importantly, support for the "adaptation" model is further provided by the only statistically significant difference in psychological functioning being found in the early stages of ageing (55-64). Evidently, research comparing the well-being of target parents across the life-span, or longitudinal studies would enable firmer conclusions to be drawn.

Social well-being. Regarding social well-being, the review demonstrates that the friendships and leisure activities of ageing parents, whose children have LD,predominantly emerge in relation to their child's disabilities. In accordance with wider literature (Kerr & McIntosh, 2000), contact with other families of disabled children was shown to lessen feelings of isolation and engender a sense of optimism and understanding. These findings can be seen to accord with the “adaptation” hypothesis, which posits that caregivers adapt to their situation by using the resources available, in order to best manage their role as caregiver (Lawton et al., 2000). However, embedding oneself almost exclusively in such networks may reduce parents’ abilities to live their own lives, potentially negatively impacting their sense of self (Woodgate, Ateah,& Secco, 2008). Whilst these parents’ social lives may look different to those of parents of TDC, the review did not identify any significant differences in the size of relational networks or extent of social engagement between these two parent populations. However, these comparisons are based on limited data and, as such, are tentative.

In addition, the review suggeststhat caregiving impacts parents’ availability to spend time with partners, non-disabled children and grandchildren.Research indicates that the distancing of family members, due to the demands associated with caregiving, can engender conflict within both the marital dyad and the extended family (e.g. Dyson, 2010). This suggestion accords with the Family Systems-Illness Model, which posits that, in families where disability is present,limited communicationinvokes tension (Rolland, 1999). Whilst the studies in this review did not examine relational difficulties per se, parents’ limited availability highlights a risk for potential familial conflict.

Additional critique. In addition to the aforementioned discussion, several other aspects of the included studies warrant critique. Firstly, the majority of studies used population norms to provide comparisons of well-being. However, several of these norms were not specific to an ageing population, and one study used norms derived from individuals aged 18-64. In accordance with gerontology literature, physical health is shown to decline with older age (Yashin et al., 2007), and psychological well-being is typically represented by a U-shaped curve; declining during middle age and subsequently increasing at approximately 50 years (Blanchflower & Oswald, 2008). As such, the physical and mental health of target parents and populations norms may well have differed on life-stage alone, resulting in requirement for considerable caution when interpreting these findings in relation to the presence of a child’s disability. Clearly, future research would benefit from comparing the target sample to ageing parents of TDC, in addition to an age-matched non-parenting population. A further critique regarding the use of general population norms concerns gender. Whilst studies provided limited information regarding the characteristics of normative data, it is likely that these groups contained more males than the target study samples. Given research highlighting gender differences in physical and mental health (e.g. Afifi, 2007; Denton, Prus,& Walters, 2004; Lansford, 2018), further interpretative caution is necessary.

Additionally, it is important to note that all studies assessed subjective well-being. Whilst this is important in determining individuals’ self-perceptions of their well-being, one’s beliefs, values and expectations generate bias (Lucas, 2018). Indeed, Baker, Stabile and Deri (2004) illustrate limited differences in self-reported health and well-being across a variety of illnesses, despite significant variance in severity. The presence of bias may be even more prevalent in ageing parent caregivers, who may be concerned as to the impact of any admission of poor functioning. As such, objective measures of health and well-being (e.g. recorded visits to GP, diagnoses) may have provided additional insight into the functioning of ageing parents whose children have LD.

Finally, whilst four studies collected data associated with parent caregivers' socioeconomic position (household income or social class), none made reference to this variable within the analysis. Given the association between learning disabilities, health inequalities and lower socioeconomic status, it is important to acknowledge the possible impact of such factors when considering the findings of this review. Research indicates that individuals with learning disabilities and their families are more likely to be living in disadvantaged circumstances compared with families where no disability is present (e.g. poverty, lower household income, and unsuitable housing conditions); factors which are associated with poorer physical, psychological and social well-being (Public Health England, 2015).As such, the limited differences between the well-being of ageing parent caregivers and controls/normative data, as outlined by this review, is perhaps surprising.

However, previous research demonstrates a relationship between increased disability severity and lower socioeconomic status (Raouafi, Achiche, & Raison, 2018). Considering that the majority of parents in the present review identified their son/daughter as having a moderate learning disability, it is possible that the reviewed studies included fewer families from socially disadvantaged backgrounds. Furthermore, research highlights an association between lower socioeconomic status and increased difficulties accessing healthcare and support services (Pickard & Ingersoll, 2016). Given that the majority of included studies recruited participants through support organisations, families from disadvantaged backgrounds are likely to be further misrepresented in the present review. Evidently, further research examining the relationship between socioeconomic factors and the physical, psychological and social functioning of ageing parent caregivers would enhance our understanding of those at greater risk.

Clinical Implications

Whilst this review does not highlight significant concerns regarding the well-being of ageing parent caregivers, professionals have a duty of care to identify, and attend to the needs of all those providing informal care (NICE, 2018). As such, these parents should be offered a carers assessment, provided with information on self-care and signposted to appropriate services and/or support organisations. Whilst these are documented as mandatory practices, ageing caregivers are often overlooked by professionals, and remain uninformed of available support until the family enters crisis (Keatinge, 2014). This may be due to the fact that, in general, these parents appear to be functioning well. However, present findings tentatively suggest that some aspects of well-being may decline with age and, as such, early provision of initial resources and/or support may prove invaluable, should parents experience future difficulties.

Whilst the present review does not wholly support wider literature, which demonstrates increasing rates of physical health deterioration in parent caregivers aged over 65, interpretative caution is required. As such, professionals should advocate attendance of free annual health checks. Additionally, given the relationship between reduced social support and decreased psychological functioning, promotion of carer support groups is imperative. Of note, it is important to ensure that the accessibility of advice and/or support information is tailored to suit individual need. For example, individuals in the latter stages of late-life typically report less online use. The resources available to them may therefore be more limited, and as such, professionals should ensure that the medium of information is appropriate.

Although there is no indication of increased risk for clinical depression in this population, it is important to acknowledge that, statistically, some ageing parent caregivers will require referral to mental health services. Professionals working in these services must consider how additional care demands may impact their ability to engage with interventions, and should endeavour to accommodate the needs of these individuals. Indeed, they may require more flexible appointment times, and understanding that cancellations at short notice may be unavoidable.

Finally, it is important to recognise that demands placed on ageing parent caregivers may rise, should LD specialist services continue to face reductions in funding. As outlined in this review, increased care-load may significantly reduce the psychological well-being of this parent population. As such, it is imperative that clinicians monitor the functioning of ageing caregivers, particularly during this time of economic challenge. From a systemic standpoint, potential decline in parental well-being presents wider challenges to LD services. Indeed, Newland’s (2015) Theory of Change model posits that parental functioning directly influences a child’s well-being. Considering that many individuals with LD remain strongly embedded within the parent-child dyad (Baum, 2018), reduced parental functioning may engender further difficulties for their offspring, in turn, heightening demand for service support. Early identification and management of declining parent well-being may therefore serve to avert additional pressure on LD services.

Strengths, Limitations and Future Research

It is important to acknowledge several strengths and limitations associated with the present review. Firstly, the exclusion of papers prior to 2005 positions the review within the current context of economic challenge, thereby only reviewing well-being during this ongoing period of difficulty (Malli, Sams, Forrester-Jones, Murphy, & Henwood, 2018). Secondly, the specific focus on LD provides an important examination of this population, within their own right. Whilst it resulted in the exclusion of several key research studies examining the well-being of ageing parents of individuals with a broad spectrum of developmental disabilities (e.g. Magaña & Smith, 2006; Seltzer et al., 2011), the review explicitly acknowledges the differing challenges raised by physical and intellectual dysfunction (WHO, 2011). The exclusion of research on this basis highlights a wider limitation with regards to the conceptualisation of certain disabilities, ultimately resulting in collective examination and the blurring of populations with, and without intellectual impairment. Future research would therefore benefit from more exclusive participant samples.

With regards to limitations, the review incorporates a small number of research papers, and the results presented are therefore based upon somewhat limited research. Further examination of social well-being, in particular, is required, as loneliness has been shown to be a prominent predictor of low QOL in older caregivers and the wider population, more generally (Ekwall, Sivberg & Hallberg, 2005). Given the conflicting nature of the findings outlined, the well-being of ageing parents of children with LD would benefit from continued research. In particular, additional longitudinal research would contribute to an understanding of any changes in their well-being over the course of the ageing process, which would enable future literature reviews to consider specific populations most at risk. Additionally, the present subject area would benefit from further qualitative exploration of factors considered to impact the well-being of parents with LD offspring, alongside the ways they manage the difficulties presented. This information would prove invaluable in enabling professionals to best support this population.

Thirdly, the study samples included in this review consisted predominantly of mothers. As such, the experiences and needs of ageing fathers remains largely unknown, ultimately requiring further research. Finally, due to the rather limited research examining ageing parents whose children have LD, this review incorporates studies across a range of countries. However, parental well-being may be influenced by disparity in healthcare systems, in addition to wider cultural differences and, as such, future reviews may wish to consider focusing on studies conducted in the same country.

Conclusion

This systematic review did not highlight particular concerns for the well-being of ageing parents of children with LD. General trends in the data illustrated that target parents exhibited slightly poorer psychological functioning. Given larger differences outlined in wider research examining younger parent caregivers of children with LD, these findings tentatively support the adaptation hypothesis. Overall, ageing parent caregivers reported good social well-being. However, their relationships and leisure activities are dominated by their child with LD, and they reported less opportunity to spend time with the wider family system. The review highlighted conflicting findings with regards to parents' physical health, for which possible reasons are discussed.

Given the various limitations associated with the reviewed studies, the results must be interpreted with some caution. As outlined, well-being may be differentially impacted across the ageing process. Further research is therefore required to explore parental well-being at varying stages of later life. Whilst these caregivers may not present with significantly reduced well-being, clinical practitioners must not neglect the importance of assessment and signposting.

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Appendices

Appendix A: Author Guidelines for British Journal of Learning Disabilities

Author Guidelines

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1. GENERAL

Aims and Scope

British Journal of Learning Disabilities is an interdisciplinary international peer-reviewed journal which aims to be the leading journal in the learning disability field. It is the official Journal of the British Institute of Learning Disabilities. It encompasses contemporary debate/s and developments in research, policy and practice that are relevant to the field of learning disabilities. It publishes original refereed papers, regular special issues giving comprehensive coverage to specific subject areas, and especially commissioned keynote reviews on major topics. In addition there are reviews of books and training materials, and a letters section. The focus of the journal is on practical issues, with current debates and research reports. Topics covered could include, but not be limited to:

- Current trends in residential and day-care services
- Inclusion, rehabilitation and quality of life
- Education and training
- Historical and inclusive pieces [particularly welcomed are those co - written with people with learning disabilities]
- Therapies
- Mental health issues
- Employment and occupation
- Recreation and leisure
- Ethical issues, advocacy and rights
- Family and carers
- Health issues
- Adoption and fostering
- Causation and management of specific syndrome
- Staff training
- New technology
- Policy critique and impact

Its readership is wide comprising members from the British Institute of Learning Disabilities, as well as academics, family carers, practitioners, staff in health and social care organisations, as well as a wide range of others with a personal and professional interest in learning disability, and who wish to promote enriched lifestyles, as well as high quality services and support for adults and children with learning disabilities.

The *British Journal of Learning Disabilities* crosses all professional groups and all academic disciplines concerned with learning disability. The opinions expressed in articles, whether editorials or otherwise, do not necessarily represent the official view of the British Institute of Learning Disabilities and the Institute accepts no responsibility for the quality of goods or services advertised.

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Please note that we also welcome articles by or with people with learning disabilities.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Papers based on original research involving people with learning disabilities must include an ethical statement to confirm either that the research has received formal ethical approval from an appropriate ethics committee or that the research has taken appropriate steps with regard access, informed consent, confidentiality and anonymity. **Contributors to the article other than the authors accredited should be listed under an Acknowledgements section which should also include, if appropriate, details of any potential conflict of interests.**

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4. MANUSCRIPT FORMAT AND STRUCTURE

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Main Text: The text should then proceed through sections of Background/Introduction, Review of Literature, Research Questions/Hypotheses, Materials, Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style

Abbreviations and symbols:

All symbols and abbreviations should be clearly explained. Abbreviations should not be used when they refer to people (e.g. learning disabilities, not LD; developmental disabilities, not DD; intellectual disabilities, not ID). Please also use “people with learning disabilities” wherever possible, not “learning disabled people”.

References: APA – American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

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Example of reference with 2 to 7 authors

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Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. Brain, 126(4), 841–865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., … Carroll, J. (2004). Sex differences in developmental reading disability: New findings from 4 epidemiological studies. Journal of the American Medical Association, 291(16), 2007–2012. doi: 10.1001/jama.291.16.2007

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SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

EMPIRICAL PAPER

Sibling discourses of future planning for individuals with learning disabilities: An exploration of taboo

Trainee Name:	**Bronwen Royall**
Primary Research Supervisor:	**Dr Janet Smithson**
	Senior Lecturer in Psychology
Secondary Research Supervisor:	**Dr Alicia Smith**
	Research Tutor, University of Exeter
Target Journal:	British Journal of Learning Disabilities
Word Count:	8258 words (excluding abstract, table of contents, list of figures, references, footnotes, appendices) – Permission granted for additional 10% for amendments.

Submitted in partial fulfilment of requirements for the Doctorate Degree in Clinical Psychology, University of Exeter

Accessible Summary

- Siblings of people with learning disabilities were asked to talk about how their families plan the future care of their brothers or sisters.
- Siblings find it hard to talk about planning the future for their brother or sister. It raises several difficult topics, including death, disagreement and choice.
- Siblings avoid talking about the future to protect themselves from feeling worried, to stop other people thinking badly of them and to make sure family members get along together.
- It is important that professionals include siblings when meeting with people with learning disabilities and their families, particularly when they talk about the future. This might help families to plan together and enable siblings to say how they feel.

Keywords: learning disabilities, siblings, future care planning, taboo discourses

Abstract

Background

Given the enhanced life expectancy of individuals with learning disabilities, siblings are increasingly adopting caregiving responsibilities when parents are no longer able. Therefore, future care planning in families is significantly important; however, previous research highlights challenges with this process. To date, research has primarily focused on future planning from parents' perspectives. This study explores how siblings talk about the future care planning process within the family context, attending specifically to taboo discourses.

Materials and Methods

Twelve siblings of individuals with learning disabilities were interviewed about planning the future care of their brother and/or sister. The data were subsequently subject to discourse analysis.

Results

Siblings were reluctant to engage in explicit future planning discussions, which drew on several taboo topics including death, conflict and obligation. Consequently, siblings employed multiple discursive strategies to evade, manage and negotiate troublesome talk.

Conclusions

In addition to parents, siblings also pose a barrier to future planning. Avoidance of discussion may shield them from criticism and vulnerability, whilst also protecting familial relationships. Professionals need to recognise the challenges these conversations raise for siblings. They should endeavour to involve siblings, in order to facilitate open dialogue and collaborative future planning.

Introduction

A learning disability (LD) is defined as a significantly reduced ability to comprehend new or complex information, alongside difficulties coping independently. Impaired intellectual and social functioning must be present prior to adulthood, and have enduring effects on one's developmental trajectory. LD are classified as mild, moderate, severe or profound and, whilst they may occur independently, they may be accompanied by additional sensory, physical or communication difficulties (Department of Health, 2001). Presently, the estimated UK prevalence of LD is 2.5% (Public Health England, 2016). However, estimates are primarily derived from support service data and, as such, true figures are likely to be higher (PHE, 2016).

Approximately two thirds of adults with LD reside within the family home, with parents acting as their primary source of support (Emerson & Hatton, 2008). Previously, shortened life expectancies of those with LD permitted their lifetime care to be the sole responsibility of their parents; however, as a result of medical advancements and enhanced social conditions, the number of individuals outliving their parents has risen significantly (Emerson & Hatton, 2008). Whilst the vulnerability of this population dramatically increases once parents are no longer able to provide care, insufficient government funding has limited the support that LD services are able to offer (Sully & Bowen, 2012; McClinton, 2016). As such, siblings are increasingly recognised as playing an important role in continuing care (British Institute Learning Disabilities, 2017). Bigby (1998) highlights the varied responsibilities assumed by siblings, including decision-making, managing affairs, supporting social engagement and adopting full-time caring roles.

This significant societal shift results in increased requirement for future care planning; that is, decisions of where, and by whom the individual will be supported once the primary caregiver is no longer able (National Institute for Health and Care Excellence, 2018). The absence of advanced planning can have significant negative consequences. When parents unexpectedly cease care duties, individuals with LD can be placed in inappropriate residential settings, and subject to multiple placement transfers, negatively impacting their well-being. When siblings assume responsibilities in the absence of comprehensive preparation, they can experience heightened levels of stress, ultimately impacting their caregiving capacity (NICE, 2018). In accordance with family life-cycle theory, adopting such responsibility interferes with the sequential pattern of transitional life stages embedded within society, thus deviating siblings from their anticipated life trajectory (Carter & McGoldbrick, 1988). The theory posits that individuals experience greater stress during transitional periods. Furthermore, transitions or significant life-events which occur unexpectedly or ‘off-time’ result in additional elevations of stress, due to their potential for skewing and disrupting individual or family goals (DeMarle & le Roux, 2001; Rolland, 1999).

Despite organisations strongly advocating future planning, the process engenders significant anxiety for parents (Hubert & Hollins, 2000; Mansell & Wilson, 2010). Many exhibit strong feelings of reluctance, with those reportedly unready or unwilling to be as high as 55-82% (Bowey & McGlaughlin, 2006; Prosser, 1997). This reluctance has been associated with multiple factors, including denial, difficulties transferring responsibility, interdependency, parents being in good health and a lack of information (Bibby, 2013; Bowey & McGlaughlin, 2006). An additional factor concerns parents’ struggle with the notion of siblings inheriting their care responsibilities. Despite many expressing an implicit assumption, expectation or hope that siblings will accept ultimate responsibility (Hole, Stinton & Wilson, 2013; Prosser, 1997), parents often fear the burden this may create (Dillenburger & McKerr, 2011; Prosser, 1997). Consequently, it seems parents refrain from entering into open discussions concerning the future (Davys, Mitchell & Haigh, 2010), and in families where these conversations do occur, sibling involvement is often limited to financial arrangements and guardianships (Heller & Kramer, 2009).

Avoidance of future planning draws on the Family Systems-Illness Model (FSIM), which suggests that communication about disability is often blocked by reluctance to explore new territory or express difficult thoughts and feelings (Rolland, 1987; 1999; Rolland & Walsh, 2006). However, such restricted communication generates uncertainty and prevents the alleviation of catastrophic fears, ultimately resulting in distress and frustration for siblings (Davys et al., 2010). The model strongly advocates the importance of communicative practices, purporting openness to enhance one’s ability to cope with adversity. A family resilience framework shares this view, proposing communication to promote resilience by providing clarity, encouraging expression of opinions and affording opportunity for collaborative problem-solving (Walsh, 2003).

Whilst little communication dominates many sibling experiences, some acknowledge open familial discussion about future planning. However, the emergence of conflicting views is common, and siblings frequently report a lack of acknowledgement and/or acceptance of their views (Davys, Mitchell & Haigh, 2011; 2015). In accordance with the FSIM, diminished consideration given to the opinions of others, and the tendency of parents to consider the responsibility as exclusively theirs, likely creates power imbalances and control within the family (Rolland, 1999). As such, it outlines the importance of viewing the “problem” as a family dilemma, arguing that this promotes resilience, empowerment and prevents guilt, resentment and relational dissolution.

Present Study

To date, research examining future planning for individuals with LD has focused primarily on parents’ experiences and concerns. Given the increasing need for involvement of siblings in future care, it is important to enhance the empirical literature pertaining to siblings’ views. The present study draws specifically on systemic theories, including the FSIM and family resilience framework, when considering the process of future care planning. These outline the importance of familial communication and sharing the dilemma when considering disability within families. However, as indicated, parents are often reluctant to participate in future planning discussions which, according to the FSIM, engenders power imbalances and tensions within the family system. Given these difficulties, it is important to consider the challenges siblings may encounter when engaging in these discussions.

Research Aims

This study explores how siblings of individuals with LD talk about future planning within the family context. Specifically, the research aims to attend to the taboo discourses that dominate siblings’ future planning talk.

Method

Research Design

Systemic thinking is pertinent to the field of LD as it emphasises an individual’s context and the gathering of multiple perspectives; factors which are paramount, given that individuals with LD are strongly influenced by the systems that surround them (Baum, 2018). Considering the systemic principles and theories underpinning this research, this qualitative study employed discourse analysis (DA) to examine interview data from siblings of individuals with LD. DA is considered appropriate for systemically-orientated research, as both discourse analysts and systemic practitioners adopt a constructionist approach to understanding how individuals shape and experience their world. As such, they are underpinned by similar theoretical and epistemological positions (Tseliou & Borcsa, 2018). Furthermore, they similarly express an interest in the impact of societal discourses on interaction and the deconstruction of meaning (Burck, 2005; Burman & Parker, 2016; Gale, 2010; Macleod, 2002).

More specifically, the analysis draws on guidelines outlined by Georgaca and Avdi (2012) to explore, and attend to, taboo discourses and the construction of interactional difficulty when siblings discuss the process of future planning. Within a DA frame, the notion of taboo is perhaps best conceptualised by the idea of topic avoidance, as defined by Dailey and Palomares (2004). They consider topic avoidance to be a “goal-oriented communicative behaviour whereby individuals strategically try to keep a conversation away from certain foci” (Dailey & Palomares, 2004, pp.472). They further posit that such avoidance has relational, individual and informative functions. Whilst, to my knowledge, topic avoidance is unexamined within the context of family disability, the concept has been considered within broader familial contexts (e.g. Guerrero & Afifi, 1995).

Participants

The study was advertised on social media channels, by charitable organisations and at Bristol and Exeter Universities. Twelve siblings volunteered between April and December 2018. Participants were required to be aged at least 18 years. Considering the research's focus on LD, siblings of individuals with Autism Spectrum Disorder, a learning difficulty or those with cognitive difficulties following acquired brain injury in adulthood, were excluded.

Relevant demographic data was collected. The sample consisted of two male and ten female participants. Participants were all White British, aged between 24 and 55.More detailed demographic information was not considered appropriate to include as, in accordance with a DA approach, considering individuals within the parameters of pre-defined categories can elicit unwarranted assumptions (Wood & Kroger, 2000).

Procedure

Ethical considerations. The study was granted ethical approval by the University of Exeter Research Ethics Committee (Appendix A). Prior to interview, participants were given an information sheet outlining the study's voluntary nature, their right to cease participation and withdraw data. Confidentiality and anonymity processes were also emphasised (Appendix B). Participants were afforded an opportunity to ask questions and provide signed consent (Appendix C). A debrief sheet was subsequently provided (Appendix D).

Interview process. A semi-structured interview schedule was developed, which examined participants' involvement in their siblings' care, their understanding of future plans and their experiences of discussing the future with their family (Appendix E). In accordance with DA, the interview schedule acted as a broad framework, providing the interviewee with scope to discuss additional areas of importance and clarify unclear talk (Barriball & While, 1994; Starks & Brown-Trinidad, 2007).

Two pilot interviews assessed the relevance, order and wording of questions (van Teijlingen & Hundley, 2001). Subsequently, 12 research interviews were conducted, ranging 27-78 minutes in length. I, as researcher, transcribed the interviews, following which sections of text incorporating taboo discourses were identified. These sections were subsequently subject to in-depth analysis.

Method of Analysis

The data were analysed using DA; an approach, which positions talk and text as the object of study. DA examines language in use, emphasising in particular the role of language in construction and function, within specific interactional contexts. Indeed, language is considered to construct, rather than mirror a social reality, and is regarded as a form of social action, in which individuals *do* through talk (Georgaca & Avdi, 2012). DA examines how speakers position themselves within specific interactions and wider discourses, considering the function of such subject positioning and the impact on constructed identities (Davies & Harré, 1990). It also considers the relationship between discourses and institutional practices, and the power of discourses in enabling, maintaining and challenging certain practices. Lastly, DA explores how the locating of oneself in particular discourses impacts subjectivity.

Georgaca and Avdi (2012) outline several levels of analysis related to the abovementioned aspects of DA (Table 1). The present research focuses predominantly on the construction of taboo topics, examining how siblings evade, negotiate and manage troublesome talk. It further considers how siblings position themselves, both within their family system and wider societal discourses. These aspects draw primarily on levels one, two and three, respectively; however, the analysis attends to all five interrelated levels.

Whilst there is no set DA procedure, several guides are available (e.g. Gee, 2014; Potter & Wiggins, 2007). These outline several broad processes, including immersing oneself in the data, compiling a data corpus and subsequently selecting, analysing and revising chosen extracts, whilst maintaining a reflexive position.

Table 1

Levels of analysis in accordance with Georgaca and Avdi (2012)

Level of analysis	Description
Level 1:Language as constructive	Analysing the ways discourses construct the object of study
Level 2:Language as functional	Examining the ways language serves particular interpersonal functions.
Level 3:Positioning	Examining how speakers use discursive practices to construct identities and position themselves within specific interactions and wider discourses.
Level 4:Practices, institutions and power	Analysing the relationship between discourses and institutional practices. Considering how discourses enable, maintain and challenge particular narratives.
Level 5:Subjectivity	Examining how adopting particular subject positions impacts the ways individuals think, feel and experience themselves.

Analysis Validation

DA considers it impossible for a researcher to assume a position of neutrality. Indeed, research is considered a discursive activity from which the researcher cannot be separated (Taylor, 2001). This rejection of the social world as independent of one’s own constructions refutes the notion of an objective truth, resulting in discourse analysts adopting an alternative conceptualisation of research validity. DA evaluates research by considering the coherence and fruitfulness of analyses (Jørgensen & Phillips, 2002). That is, analytical claims should be observable within the discourse, ultimately generating a coherent narrative. As such, the current analysis is grounded within previous research and supported by the inclusion of data extracts. Additionally, I regularly attended a DA research group, in which aspects of the data were presented and discussed. The analysis was also reviewed by a discourse analyst (primary supervisor). Regarding fruitfulness, findings should be both relevant and novel. To this end, I presented the research findings to professionals working in LD services and, more widely, at a Special Interest Group conference.

Analysis

In the following section I present six extracts, which represent various taboo discourses that emerged in participants' talk. In addition to selecting highly representative sequences of discourse, extracts which display features pertinent to DA have been chosen (Jørgensen & Phillips, 2002).

Extract 1: Future Planning as Taboo

The first extract comes mid-way through the interview with Lexie[1], following a discussion in which she describes her growing realisation that she is embarking on a non-typical future.

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[1] All participant names and the names of significant others have been replaced with pseudonyms

Interviewer: When you talk about the future with your parents, what’s that kind of process like? In terms of how does it happen?

Interviewee: Erm [1] generally it sort of just happens naturally, spontaneously because out of another conversation, whether that be a conversation about [0.3] Sarah specifically and what’s going on for her or the conversations they’ve had, or changes to her care plan or to her finances [slowing speech], that my parents have sort of said, oh F.Y.I you might need to know [0.3] erm [0.2] this, this and this is what’s going on. Erm [1] there’s been a couple of conversations more spe like very specifically about the future that have come from other conversations. So for example erm [0.2] talking about my relationship with my partner and me sort of saying to my mum, oh one thing I really like about Liam is that he sees Sarah as his sister and I know that he’s really there for Sarah and erm that’s really nice. Those kinds of conversations that have started more to do with me and my life and thinking about my future that I’m now building with my partner. Erm [1.5] I think there’s also a few that have come out of [0.1] slight [0.1] tensions between me and my brother [subtle smiling/laughter] over various things that haven’t got anything to do with Sarah [quickened speech]. But I’ve talked to my mum about them and to my dad about those and sort of said ooh one of the things that frustrates me is [1.8] my brother has a tendency to talk about Sarah as though she’s a bit of a burden [rise in pitch] [quietened speech] and like oh isn’t it annoying how she phones every night.

At the beginning of the extract, Lexie describes future planning as emerging “out of another conversation”, constructing it as supplementary to a wider discussion, rather than warranting consideration in its own right. This discursive lessening of its significance and complexity is further observed by the abbreviated colloquialism F.Y.I (353), alongside the rapid and non-explicit speech that follows (353-354). The dictating nature of this reported speech closes down the discussion, ultimately positioning Lexie's parents as the dominant party, denying her any choice or opinion. Additionally, the use of "might" (353) creates ambivalence about Lexie's need for information, further dismissing her involvement. These discursive practices construct an imbalance of power, which accords with the FSIM's suggestion that parents assume sole responsibility for the disabled family member (Rolland, 1999). This perhaps reflects a sense of guilt (Ferguson, 2002) and/or their need to protect non-disabled siblings from the burden of care (Dillenburger & McKerr, 2011).

Mid-way through the extract, Lexie alters the discourse to conversations "specifically about the future". This discursive shift engenders a change in the dominant subject position from "They" to "I", thereby positioning Lexie in control of initiating specific planning talk. However, the following accounts do not speak explicitly of future plans. Instead, Lexie draws on associated discourses to subtly negotiate and express concern about the future. This incongruence mirrors previous research, which highlights that siblings' often worry about future planning conversations, forfears of heightening parental anxiety (Davys et al., 2010).

Initially Lexie constructs a positive relationship between Sarah and her partner, thereby aligning her sister with her own evolving family unit. However, repetition of the possessive pronoun "my" (360), simultaneously distances Sarah from Lexie's immediate system. Subsequently, Lexie constructs future planning as predicting, and endeavouring to resolve impending difficulties with her brother. In line 365, Lexie confesses her brother's actions by shifting the audience of her intended speech, in order to directly address the interviewer. The confessional nature of her talk, alongside her vocal changes indicates Lexie’s reluctance to be associated with a discourse of burden, thereby positioning herself within more permissible discourses of acceptance and inclusion (Carrill, 2016). Lexie’s construction of her brother further draws on a gendered discourse of care, which positions women as the traditional caregiver (Weicht, 2009). This corresponds with research demonstrating that sisters both expect, and adopt greater responsibility for disabled siblings (Egan & Walsh, 2001).

Extract 2: Future Planning as Taboo

The following extract comes towards the end of the interview with Amelia. Prior to the extract, she describes her partner as having a loving relationship with her sister, Lily. Amelia highlights the importance of her partner’s support, particularly when considering the future.

Interviewer: Have you actually kind of talked to him about the future, kind of what that might entail or what you want that to entail?

Interviewee: Yeah briefly. We, you know we’re both in agreement you know I’ve always said I’m going to have Lily if anything happens. And he’s said yep, we’ll [emphasised] have Lily. Not you’ll [emphasised] have Lily. We [emphasised] will have Lily. You know we’ll make it work no matter what you know no matter what happens and that’s sort of been it really. We’ve never had to really go too much in depth about it erm it’s just sort of that mutual agreement of yep, we’ll have Lily and that’s it.

Interviewer: And has that been a kind of sit down conversation or has it been more

Interviewee: Erm I think it's been more I've brought it up in conversation when I've spoken to my mum about it and then I've told you know I've told my boyfriend about it afterwards. And I've said look this is what I've said to my mum, like yeah I'm going to be the Trustee for her, I'm gonna be in charge of her finances. And he said like yeah, of course like you know who else would do it? You're the one. Erm and you know I've sort of said Oh God, like my mum [0.1] you know what will [emphasised] happen in the future? Erm and you know we're both in agreeance, you know it's not been like a sit down, full you know conversation it [0.1] kind of like the same with my mum really, it just [0.3] yeah, that's what's going to happen. We'll have Lily and that's it. There's no [0.5] no other way about it really [laughter].

From the beginning of the extract, Amelia constructs a strong "we" identity. Her initial emphatic use of "We" (414), the temporal transitioning of subject positions from "I" to "We" (415-416) and her construction of her partner's agreement (416-417), jointly position them when considering Lily's future care. Such unity reflects relevant literature, which outlines the importance of a cohesive familial system when managing caregiving responsibilities (Dyson, 1996; Hastings & Taunt, 2002), particularly during times of transition (Rolland, 2012).

In addition to positioning, the extract highlights the future planning taboo. With the exception of acknowledging her future role in managing Lily's finances, Amelia's discourse is largely non-explicit, with the future repeatedly alluded to by use of the term "it" (417-425). This corresponds with literature, which demonstrates that, aside from practical arrangements, sibling responsibilities remain largely undisclosed (Davys et al., 2010).Furthermore, Amelia’s reiteration of “having Lily” objectifies her, ultimately reflecting historical discourses of pathology, in which diagnostic labels serve to de-humanise individuals, reducing their complex individuality to a collective group of needs (Gillman, Heyman & Swain, 2000). This objectification minimises the complexity of Lily’s care, in turn, preventing the requirement for further discussion. Similarly, the short, sharp nature of Amelia’s language (415-417), alongside the use of the colloquial “yep” (415), actively dismisses the subject matter. This dismissal is further compounded by Amelia’s construction of certainty, as illustrated by the repeated closing down of alternatives (e.g. “we’ll have Lily and that’s it”). These findings suggest that, in addition to parents, siblings avoid in-depth future planning discussions, thereby contributing to the taboo.

Extract 3: Death as Taboo

The third extract is located towards the end of the interview with Megan. Immediately prior to the extract, Megan highlights the difficulties conversing with her parents about the future, following which she diverts the conversation to construct and negotiate anticipated future responsibilities within the context of her own marital relationship. The interviewer subsequently acknowledges the barriers to developing future plans and questions Megan about anticipated benefits of planning.

447 **Interviewee:** Erm well I think erm [2] being able to plan together [0.5] erm being
448 able to have input into what happens erm [1] knowing knowing what Lizzie
449 thinks about it as well, you know I think that would be important. And also

because I suppose [0.5] on the [0.4] if you look at it from a negative point of view, because if we don’t [laughter] then [0.5] it [0.5] there could be, you know if something happens, you know I don’t know [spoken quietly], if one of my parents suddenly was ill or suddenly wasn’t around or erm [1] almost just like a smoother, a smoother transition.

Megan alludes to the importance of planning her sister, Lizzie’s, future care, in preparation for her parents’ death. The use of “together” constructs this process as joint action; however, Megan’s subsequent downgrading to having “input” demonstrates a lack of confidence and clarity regarding her position within the process. Death is repeatedly constructed as an unspeakable event, as illustrated by avoidance of specific terminology related to death and dying. Indeed, Megan insinuates death by inviting the interviewer to consider the situation from a “negative point of view” (450) and if a parent “suddenly wasn’t around” (453). Her use of laughter further illustrates discomfort, and acts to neutralise the negative discourse. Difficulties engaging with death talk are additionally evidenced by the fragmented and prevaricating nature of Megan’s speech (449-452), as indicated by episodes of mid-sentence pausing, alongside the continuous discursive shifting, ultimately preventing the formation of a cohesive narrative. Furthermore, Megan’s hushed speech demonstrates a need to physically silence the unutterable discourse (452).

Megan’s reluctance to talk explicitly about dying corresponds with society’s primary construction of death as taboo; an unpalatable subject, which must be hidden and removed from everyday experience (Aries, 1981). The death of loved ones, in particular, provokes heightened sensitivity and upset, resulting in greater concealment (Bowen, 2018).

In addition to death as unspeakable, Megan constructs death as uncertain. This is evidenced by the ambiguity of her talk, and by her process of minimising the biologically inevitable (e.g. “there could be, you know if something happens, you know I don’t know”). The indeterminate nature of her speech represents the presence of denial; a cultural mechanism, which acts to protect the individual from emotional distress, vulnerability and unavoidable loss (Becker, 1973). Yet, despite society’s denial of death, Kübler-Ross (1969) highlights that death talk is often welcomed, providing relief and opportunities to plan appropriately. As such, combating the death taboo may reduce families’ avoidance of future discussions, ultimately facilitating care planning.

Extract 4: Managing Disagreement

The fourth extract is located mid-way through the interview with Zara. It follows a discussion in which she highlights concerns about assuming sole responsibility for her brother, Johnny. Zara further constructs her parents as dismissive and invalidating of her fears, positioning herself as the silenced party.

Interviewer: Is there any times when you and your parents kind of disagree in terms of [0.4] maybe not because it sounds like you haven’t thought about the future that far ahead, but even just day to day things?

Interviewee: Erm [1] sometimes [stretched out speech] like [0.2] for example sometimes I think maybe [0.1] they can [0.2] do too much for him erm which has maybe not made him quite as independent related to his care and things like he could be [slowed speech]. Erm so maybe [laughter] I don’t want to criticise my parents too much because I’m sure they’ve done a great job [quickened speech] but sometimes erm [0.5] with like doing the washing and things like that I think maybe because of his Dyspraxia and he’s quite clumsy sort of thing, I think maybe [stretched out speech] I’m probably guilty of this as well [quickened speech], we do we step in too quick to do things for him which has maybe made him less independent [0.1] erm than he could be for someone at his age. Err so like, this goes back to the whole life skills things, using the washing machine, personal care and stuff like that. So maybe [laughter] we could have err encouraged him to do a bit more and sometimes I do sort of say to my mum and dad, oh no leave it he can do it himself sort of thing. And they’re like, oh no but then it’ll be more work sort of thing [laughter] because there’ll be a bit more mess not that he can help it [laughter].

At the beginning of the extract, Zara constructs her parents as hindering Johnny’s independence, subtly attributing blame for his level of reliance (259-261). In doing “too much for him”, Zara’s parents are constructed as infantilising Johnny, behaviour which is prevalent among parents whose children have disabilities (Smith & Tobin, 1994). Whilst adult infantilisation is considered a contributor to heightened disability (Carrill, 2016), parental intentions are often protective (Zielińska-Król, Gorbaniuk & Mirosław, 2015). Voicing concerns may therefore engender significant distress, which perhaps explains why the discourse is rendered unspeakable. Indeed, the presence of mid-sentence pausing, alongside the slowing of her speech, highlights Zara’s physical reluctance to engage in talk that functions as criticism or challenge. Furthermore, Zara softens and downplays her critical stance, as evidenced by persistent minimisation throughout the utterance (e.g. “sometimes, I think maybe”).

Zara’s reluctance to negatively position her parents is further demonstrated by the ways in which she uses talk to build up to a disclosure of criticism. In line 261, the use of laughter highlights discomfort, whilst simultaneously attempting to disguise Zara’s impending criticism through a mask of joviality. Her subsequent commendation of her parents’ actions (262) further acts to qualify and counteract the shift to a negative discourse, as indicated by the use of “but” (263). Despite this discursive prelude, Zara’s silence is maintained by the broken nature of her subsequent discourse, which functions to stall talk of criticism and opposition (262-265). Furthermore, the sudden shift in subject positioning from “They” to “We” (266) indicates a joining of identities and, in turn, the construction of a collective blame. Zara’s confession that she is also “probably guilty” (265) emphasises this joint position, ultimately deflecting a portion of the blame.

Towards the end of the extract however, Zara retracts this joint position by reverting to original subject positions, in turn, re-distancing herself from the discourse of blame (270). This reversal serves to construct two opposing parties, with Zara positioning herself as defeated. Indeed, the utterance concludes with the reporting of a parental counter-argument (271-272), thereby positioning them as the overarching influence. As such, Zara constructs the unanswerable argument, further contributing to the notion of opposition and disagreement as taboo.

Extract 5: Freedom Vs Duty

The following extract is located towards the end of the interview with Bethan. Immediately prior to the extract, Bethan talks about the benefits associated with future planning, constructing it as a source of reassurance and comfort for her mother.

Interviewer: I suppose you've touched on this a little bit but the kind of difficulties as well associated with the future planning process?

Interviewee: [2.5] Well again I think my mum feels a bit guilty about burdening, or she calls it, she thinks she's burdening me with it.

Interviewer: Hmm.

Interviewee: On one hand but then [2.8] I almost feel like it's myyyy [1] duty? [slowed speech] Or she [2] she probably feels it's my duty as well I guess [rise in pitch]. So on one hand she feels guilty but on the next hand, if I said oh no I'm not doing that she'd be [1.5] furious [laughter].

Interviewer: Ok.

Interviewee: She'd be like it's your brother, what are you [interrupts self]. Yeah, you know?

Interviewer: Yeah, yeah.

Interviewee: Who else has he got?

Interviewer: So being torn?

Interviewee: Yeah [0.5] and that's kind of how I grew up as well. I don't want to do that. Oh but he's your brother, you need to do this la-la-la-la-la.

Interviewer: Ok.

Interviewee: So I was never, sometimes I don't feel like I was given a choice. It was just like well [0.2] he's your brother, get on with it. Stop feeling sorry for yourself.

555 **Interviewer:** Ok.

556 **Interviewee:** [Inaudible] Oh, ok. Thanks very much [spoken quietly]. I won't go
557 out then [laughter]. You know?

Bethan uses the term "burdening" (536) to construct an inevitable transfer of responsibilities. However, she subsequently retracts her association with a burdensome discourse, emphasising that the narrative belongs solely to her mother ("she calls it, she thinks she's burdening me with it"). The utterance "she thinks" further distances Bethan from burden talk, serving to deny it as her own reality. This act of distancing accords with social and cultural practices, which promote positive discourses (e.g. acceptance, inclusion and ability) in line with the social model of disability (Shakespeare, 2013).

Subsequently, Bethan tentatively constructs future responsibilities as her duty. However, the lengthy mid-sentence pause, the elongating of "my" and the slowing rate of speech (539-540), illustrates a physical reluctance to express this obligation. Posing the statement as a question further constructs uncertainty, illustrating a reluctance to commit to the notion of "duty". This corresponds with competing discourses of individualism and traditionalism. Indeed, whilst the desire for self-fulfilment and the leading of one's own life is ever-increasing in modern society, discourses of traditional familial care practices remain embedded (Beck & Beck-Gernsheim, 2002).

The presence of this traditional discourse is further evidenced by Bethan's anticipation of her mother's fury should she relinquish future responsibilities (542). As such, Bethan constructs a restricted freedom; however, her pause highlights a hesitance to construct her mother as limiting her liberty, and her concluding laughter retracts the severity of her mother's predicted response. To reduce her discomfort further, Bethan shifts the discourse from describing to performing her mother’s speech (544-550). This prevents Bethan directly positioning her mother within the declining discourse of familial duty, instead inviting the interviewer to form their own opinion. Repetition of “he’s your brother”, particularly when preceded by “but” and “well”, constructs sibling care as the expected norm, in turn closing down opportunities for negotiation. This lack of choice is further reiterated by Bethan’s positioning of her mother as the dominant, controlling party (“you need to do this”), who prevents any response by way of an extended dismissal (“la-la-la-la-la”).

This construction of restricted choice continues throughout the extract. However, the subsequent diversion of the conversation to childhood (549) demonstrates Bethan’s reluctance to position herself as a controlled adult. This taboo reflects wider societal discourses which distinguish between the controlled child and the autonomous adult (Franklin-Hall, 2013). The discomfort associated with this position results in Bethan’s attempt to detach her mother from this restrictive action, thereby protecting her from negative perception. She downgrades the extent of her limited choice, following which she demotes fact to opinion (“I was never, sometimes I don’t feel like I was given a choice”). Subsequently, Bethan uses sarcasm to demonstrate her frustration (556); however, this is minimised by the quietening of her speech, alongside the use of laughter, which serves to conceal irritation through joviality. Finally, in concluding the utterance with a question, Bethan seeks reassurance for how her talk has been perceived, thereby emphasising taboo discourses of duty, freedom and sibling defiance.

Extract 6: Freedom Vs Duty

The following extract comes mid-way through the interview with Harvey. It follows a discussion, in which he constructs his future care role as an implicit parental assumption. He further constructs his parents as protectively concealing care responsibilities, in order to shield him from the ensuing impact.

Interviewee: Erm [1.2] I mean I have started having little [0.2] conversations with my mum about this idea about getting her more independent and whether she'd want to move out at any point. Erm [1.5] and yeah just a whole host of different sort of opportunities for her to look for new work, to look for romantic relationships erm [2] and part of that conversation will be me saying because you won't always be here [1] so what is going to really be best for us [interrupts self] best for her, best for us and best for all of us? Is it going to be a situation where [0.5] she comes into [0.5] potentially a family unit erm with someone that's almost like the partner of me or the partner of Emily, that's almost [0.2] not expecting it or not signed for it erm [0.5] and the sort of threat that poses to that family system which has been working well or would you want her having some independence, having a life, potentially having a partner? Erm [1] having a home of her own? Erm [2] so yeah I think I kind of try and sneak in the backdoor a little bit with those conversations.

Interviewer: Yeah. So you kind of implementing those discussions in a sneaky sort of way.

Interviewee: [Laughter]. Yeah like in just a like [0.6] I guess it's just coming from a more positive [0.1] place. I think there's such a tendency to start those conversations erm [1] with the kind of the [1] the person like Charlotte being perceived of as the burden. Who takes on the burden? Erm [0.5] but rather than approach it from that way and it be, I don’t know such a negative thing and something that people are [0.5] like the siblings are kind of like well, oh yeah it is a big task, to start from a completely different position in terms of that conversation to be more positive and to say right, what does she want out of her life first and foremost? Not like who’s going to put up with her? How do we help her to be her best her?

At the beginning of the extract, Harvey describes his attempts to tentatively introduce his mother to the possibility of Clara becoming more independent. In referring to the conversations as “little”, Harvey minimises the discussions, in turn positioning himself as encroaching on his mother’s superiority. Similarly, Harvey later describes trying to “sneak in the backdoor” with independence talk (339), engendering a discourse of secrecy and concealment. The construction of independence as taboo demonstrates the continuing predominance of traditional discourses of familial care in the presence of disability (Power, 2016).

Importantly, there is incongruence in the way Harvey promotes independence. His reference to “getting her more independent”, positions Clara as a powerless individual, requiring change and improvement. Yet, subsequent consideration of “whether she’d want to move out”, illustrates contemplation of Clara’s voice. As such, Harvey replaces his objectification of Clara with a discourse of personhood (Agmon, Sa’ar & Araten-Bergman, 2015),mirroring the transition of societal discourses over time.

The extract also highlights conflicting discourses of individualism and traditional family care (Beck & Beck-Gernsheim, 2002). This is initially evidenced by Harvey’s reparative speech in line 332-333. Indeed, his interruption endeavours to amend his primary consideration of “us” (non-disabled siblings) to “her”, ultimately correcting the appearance of putting his own needs before those of Clara. Subsequently, Harvey poses two distinct scenarios to depict Clara’s possible future. The first, constructs her as “coming into” his family unit, positioning her as an invading outsider who poses a “threat” (336) to a well-established system. This negative construction directly opposes the second scenario, in which independent normalcy is discursively produced. Indeed, Harvey lists a series of typical life events, thereby drawing on a discourse of typical development. Furthermore, Harvey’s description of the latter option as “a life” (338), construes, by association, the former “situation” as something other – a mere existence. Ultimately, in constructing such opposing discourses, Harvey bolsters his argument for Clara’s independence, in turn regaining some of his own freedom. In order to remain within the realms of a socially accepted discourse, Harvey later reframes his encouraging of independence. He constructs his approach to future planning as distanced from burden talk, positioning it firmly within a discourse of personhood, in which Clara is centrally positioned (344-352).

Discussion

This study explored how siblings of individuals with LD construct and position themselves within the process of future care planning. The analysis demonstrates the construction of the subservient sibling, positioned beneath the powerful parent. Despite being in the throes of adulthood, siblings position themselves as the controlled child who is unable to openly express their opinion. This corresponds with the FSIM, which highlights increased parental dominance in the presence of disability (Rolland, 1999). However, the present analysis furthers this idea by contributing novel findings, with regards to how siblings manage this imbalance of power. Whilst siblings were reluctant to position themselves as in control, their careful construction and positive re-framing of situations suggests an element of covert power (Wang, 2006). As such, parents' overt dominance is met by a furtive struggle for control, suggesting siblings may have a greater degree of influence than previous research indicates.

In addition to positioning, the study focused on taboo discourses and examined how siblings negotiate and manage interactional difficulty. Future planning, itself, was constructed as taboo, with attempts to avoid the topic highly apparent in the discourse. Siblings engaged in circuitous, evasive and non-explicit speech, and employed various discursive strategies to simplify, close down and prevent further discussion. Previous literature illustrates that siblings strongly desire an involvement in the future planning process; yet, suggests that their engagement is impeded by parental reluctance (Davys et al., 2010). This study reiterates siblings' wishes to share planning responsibilities; however, it furthers previous research by demonstrating that they themselves act as a barrier to open discussion.

Considering the array of difficult topics invoked by future planning conversations, siblings' avoidance is perhaps to be expected. In these extracts, the notion of future planning was bound up with discourses of death and dying; a societal taboo, which engenders significant discomfort when relating to family (Bowen, 2018). Siblings utilised prevarication, laughter and minimisation to avoid explicit death talk; discursive strategies, previously associated with other taboo discourses (e.g. Demjén, 2016; Harrington, 1992; Tolton, 2014). For siblings of individuals with LD, parental death not only represents substantial loss, but also the inheritance of significant responsibility. As such, evasion of death talk not only complies with permitted societal discourse (Walter, 1991) but, in accordance with the notion of topic avoidance, serves as a mechanism for self-protection, enabling siblings to shield themselves from impending vulnerability (Guerrero & Afifi, 1995).

This study further highlights that siblings' opinion around future planning, which oppose those of their parents, are strictly taboo. The analysis illustrates siblings' discursive reluctance to criticise or disagree with their parents' practices. In accordance with literature on topic avoidance, it is suggested that siblings' evasion of critical disclosure is motivated by a drive to protect the parent-child relationship from conflict and dissolution (Afifi & Guerrero, 2014). In families where disability is present, relational cohesion is paramount in facilitating coping and resilience (Weicht, 2009), and as such, the protection of familial relationships is imperative. Previous research suggests that parents often dismiss the views of siblings. However, this study provides novel findings, which suggest that siblings themselvesoften refrain from explicitly expressingtheir views and opinions. As such, both parties appear responsible for interactional difficulty around this topic.

Siblings demonstrated careful management of any conflicting input, which they minimised through lessening their own opinion and constructing a joint position of blame. This balance between candour and silence corresponds with the expressiveness-protectiveness dialectical tension, whereby individuals censor their communication to ultimately maintain their relationships (Rawlins, 1983). Siblings' difficulty in voicing their opinions presents challenges for future planning. Indeed, systemic principles posit that inability to openly communicate generates "stuckness", hindering the possibility of change, resolution and, in this case, the development of collaborative future plans (Tickle & Rennoldson, 2015).

Finally, the present study identified competing discourses of sibling duty and sibling freedom, both of which engendered interactional difficulty. Siblings were reluctant to position future caregiving responsibilities within the realms of imposed duty or obligation, thereby conforming to societal and cultural customs of morality, acceptance and inclusion (Shakespeare, 2013; Weicht, 2009). However, many simultaneously alluded to their desire for freedom, in turn drawing on discourses of individualism (Beck & Beck-Gernsheim, 2002). Within Western society, the traditional family is in decline, superseded by the desire to live one's own life, have greater choice and be freed from traditional restrictions (Triandis, 2018).However, for these siblings, the endorsement of this discourse was strictly taboo. Importantly, this notion of freedom further corresponds with a desire to follow a “normal” life trajectory. Indeed, family life-cycle theory posits that during early adulthood individuals distance themselves from their immediate family, in order to commit to their own establishing systems (Carter & McGoldbrick, 1989). Despite the “normalcy” of freedom, discourses of familial care remain prevalent in families where disability is present and, as such, siblings are caught in the midst of two competing social and cultural customs.

To manage these conflicting discourses, siblings frequently promoted the enhancing of their brother/sister's independence, thereby distancing themselves from the caregiver role. However, such suggestion was positively re-framed as a shift from the confines of familial care, to the enablement of LD siblings developing their own lives. This highlights the implications of familial, societal and cultural expectations, which ultimately render siblings unable to express their own desires. Their careful management of such talk serves to facilitate their own needs, whilst protecting them from criticism and judgment (Afifi & Guerrero, 2014).In addition to balancing desire and expectation, siblings' discursive distancing from a role of care may also reflect a denial of an anticipated future reality. According to Sinason (1992), denial is a common defence mechanism employed by families of individuals with LD, which serves to protect against difficult feelings associated with familial disability, loss, uncertainty and challenge (Sinason, 1992).

Clinical Implications

This research highlights the inherent difficulties associated with future planning within families, thereby illustrating a role for services in promoting and/or facilitating this process. Siblings are often overlooked by services (Tozer & Atkin, 2015), which largely mirrors familial dynamics, and reinforces the sibling position of lessened significance. To ensure sibling inclusion, services must adopt a systemic approach when working with these families. Incorporation of systemic principles would foster open dialogue, and enable families to develop collaborative plans. Specifically, Fredman (2014) suggests professionals assume the role of "conductor" when inviting difficult conversations; a "de-centred" position, which attends to all voices present. The conductor is well-positioned to recognise, and draw on, subjugated sibling narratives, often lost amongst parental dominant discourses. From this removed position, they are also able to notice topic avoidance and reflect on the possible functions, which may underlie non-disclosure.

Given the portrayal of future planning as an evolving process, discussions should not be a one-off event. Professionals should continually invite conversations, incorporating them into assessments, interventions and review procedures. Facilitating open communication would not only normalise these conversations and support collaborative planning but, in accordance with the FSIM and family resilience framework, diminish imbalances of power, reduce anxiety and promote positive familial relationships. As such, it may alleviate broader familial difficulties, in turn lessening the demands for service support. In some situations, the involvement of siblings may be hindered by parental reluctance. In such instances, professionals should name this dilemma, offer education and help parents to reflect on their reluctance. Even in their absence, siblings should inform formulations, in turn, endorsing and validating their position within the system.

In addition to future planning difficulties, this study highlights siblings' battle between living their own life and assuming a caregiver role. It must be recognised that ensuing responsibility not only engenders uncertainty and concern, but potentially hinders siblings' life choices. It is therefore imperative that support is offered (e.g. carer assessments, family interventions or signposting). Finally, it is imperative that in attending to multiple familial voices, professionals continue to hold the individual with LD at the centre of any conversation. As demonstrated by this analysis, objectification of individuals with LD causes planning to occur in their absence. Professionals must therefore carefully balance the incorporation of all systems, whilst remaining mindful of the individual around whom they are centred.

Limitations and Future Research

One limitation associated with DA concerns its limited generalisability. Discourse analysts assert that "discourse is occasioned", that it is constructed within specific interactional and interpretative contexts (Gill, 2000, p. 175). A further limitation concerns the sample’s cultural homogeneity. From a social constructionist perspective, disability is discursively situated within social, cultural and institutional practices (Devlieger, 1999) and, as such, familial narratives regarding disability management and sibling involvement vary cross-culturally (e.g. Ghaly, 2016; Harry, 2002). Differences in siblings’ future planning discourses may occur, highlighting the need for additional research exploring a variety of cultural backgrounds. Furthermore, understanding cultural differences would enable services to better support families with future planning. In addition to limited cultural representation, this sample comprised primarily of sisters. Given traditional gendered discourses of care (e.g. Weicht, 2009), brothers’ and sisters’ discourses may vary and, as such, further research examining brothers’ accounts is required. Similarly to above, this would better enable services to respond to the needs of individual siblings.

Overall, this research provides a novel contribution in considering how siblings manage taboo topics, which future planning discussions draw upon. However, to further extend this research, similar exploration of parental talk may highlight additional interactional barriers to future planning discussions. Given that DA favours naturalistic conversation rather than interviews (an additional limitation of the current research), future studies should consider conducting focus groups with parents/families. Finally, DA of family assessment/therapy sessions would offer a valuable insight into future planning talk within the context of service involvement. This would enable additional consideration by professionals as to how best facilitate and/or manage these discussions.

Researcher Reflexivity

As DA involves a process of deconstruction (Parker, 1988), aspects of the researcher’s own social context, which may influence the analysis, must be acknowledged to ensure transparency and accountability (Taylor, 2001). As such, it is important to consider the ways in which this research topic resonates with me, both personally and professionally. As a sister of someone with a LD, Iam familiar with the benefits associated with future planning. However, I have experienced various challenges when engaging in these conversations and, as such, this research reflects my curiosity regarding wider discourses and my endeavour to promote the sibling voice. Given my personal background, it is important to acknowledge that, when conducting the present analysis, I may have favoured particular narratives closely related to my own experiences or overlooked negative discourses, in order to present a favourable image of the sibling population.

In addition to a personal resonance, my interest in this topic stems from previous employment within the learning disability sector. I have witnessed professionals’ frequent neglect of siblings, often overlooking the involvement of this particular population when considering an individual’s present and future care. The research is therefore influenced by my desire to aid professionals in increasingly valuing, promoting and encouraging wider familial support when considering the future. Importantly, given that much of my professional background is embedded within psychology, it is necessary to consider the potential influence of these experiences on the research process. DA principles of language as constructive largely conflict with the use of language in clinical psychology practice, in which it is primarily used to conceptualise individuals’ underlying mental states. Attending solely to what/how language is produced, and ignoring psychological assumptions which may be attributed to such talk, has therefore required a deviation from familiarity.

Conclusion

This study, which examined how siblings discursively manage taboo discourses associated with future planning, provides a novel and valuable contribution to the current sparse literary base. Whilst siblings desire to be involved in future planning, they are reluctant to explicitly discuss the subject matter. This is unsurprising considering the various taboo topics that future planning conversations engender. Siblings demonstrated that discussions provoke talk of parental death, familial disagreement, obligation and desired freedom, ultimately resulting in their employment of multiple discursive strategies to evade, manage and tentatively negotiate such interactional difficulty. In accordance with literature on topic avoidance, it is suggested that such discursive management serves to shield siblings from vulnerability and criticism, protect familial relationships and ensure conformity to wider societal and cultural customs.

Given the increasing recognition of siblings as future caregivers, collaborative future planning is essential in ensuring the alleviation of anxiety for all parties concerned. The difficulties associated with these conversations, highlighta role and opportunity for professionals to promote and facilitate both future planning discussions, and the involvement of siblings in their brother/sister’s care.

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Appendices

Appendix A: Ethical Approval

CLES – Psychology
Psychology
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CLES – Psychology Ethics Committee

Dear Bronwen Royall

Ethics application - eCLESPsy000364
Future care planning for individuals with learning disabilities: Taboo and permitted discourses

Your project has been reviewed by the CLES – Psychology Ethics Committee and has received a Favourable opinion.

The Committee has made the following comments about your application:

If you have received a Favourable with conditions, Provisional or unfavourable outcome you are required to re-submit for full review and/or confirm that committee comments have been addressed before you begin your research.

If you have any further queries, please contact your Ethics Officer.

Yours sincerely

Date: 20/02/2018

CLES – Psychology Ethics Committee

Appendix B: Participant Information

Information for participants

Hearing the sibling voice... Future care planning for individuals with learning disabilities

Contact details of Principal Investigator:

Bronwen Royall
Doctoral Student in Clinical Psychology
University of Exeter
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Telephone: 07714255521

Invitation

As part of my Clinical Psychology doctoral training, I am investigating how siblings of individuals with learning disabilities talk about the process of planning the future care of their brother or sister. I am therefore inviting siblings to take part in an interview to discuss this topic area. In order to participate in the research study you must be aged 18 years or above, and your brother or sister must have a diagnosed learning disability.

Purpose of the study

Whilst siblings of individuals with learning disabilities are adopting an increasing role in the future care of their brothers and sisters, much of the available research literature indicates that parents often avoid open family discussions regarding future planning. Moreover, in families where these conversations do occur, sibling involvement is often limited to topics concerning financial arrangements and guardianships. By hearing siblings talk about future planning, this research aims to gain a better understanding of how this process is talked about and constructed among the family.

The findings of this research study may have implications for professional guidelines and clinical practice.

Involvement in the study

Participation in this research study will involve taking part in an interview, in which you will be asked to discuss your thoughts and personal experiences relating to the process of future planning for your sibling with learning disabilities. The interview is expected to last approximately one hour.

The interview will be tape recorded, and subsequently transcribed by the researcher or an independent, external agency. Following transcription, the data will be subject to analysis, and once completed, the findings will be written within the empirical paper of a Clinical Psychology Doctoral thesis. This paper may contain direct quotes of participants’ responses, however all quotes will remain anonymous. It is anticipated that this empirical paper may be submitted for publication in an academic journal, and further requested to be presented at an appropriate academic conference. Participants may request a summary of the research findings once completed.

Psychology students from the University of Exeter will be provided with 1 course credit for participation. Other individuals who wish to participate will be entered into a prize draw to win a £50 Amazon voucher. Importantly, should participants wish to withdraw from the study, they will still receive the course credit/entry into the prize draw.

Potential risks and ethical considerations

During the interview participants will be asked to consider and discuss their thoughts, opinions and experiences of having a sibling with learning disabilities, and will specifically focus on the process of planning their future. Given the personal and sensitive nature of this topic, it is possible that participation may cause distress to some individuals.

Ethical approval for this research study has been granted by the University of Exeter.

Confidentiality

All information provided by participants will remain anonymous and be kept confidential. The only exception to this would occur in the unlikely event that participants’ discussions indicate risk of harm to themselves or others, or raise safeguarding concerns.

All participants will be identified by pseudonyms. Information gathered during the research process, including audio recording and transcripts will be stored securely and destroyed once the research project has been completed.

Withdrawal

Participation in this research study is voluntary and participants may therefore leave the interview at anytime. It is also possible to withdraw your data once you have participated, however, you must notify the researcher with this request within one month of participation in order to ensure that your data is removed before commencing the analysis. Please note that you are not required to provide a reason for withdrawal.

Thank you for taking the time to read this information sheet. Should you have any further questions regarding participation, please do not hesitate to contact the researcher on the details provided above. Should you wish to participate, please sign the consent form attached, and return it to the researcher.

Appendix C: Participant Consent Form

Consent Form

Hearing the sibling voice... Future care planning for individuals with learning disabilities

Contact details of Principal Investigator:

Bronwen Royall
Doctoral Student in Clinical Psychology
University of Exeter
Email: br300@exeter.ac.uk
Telephone: 07714255521

☐ I have read and understood the information sheet relating to this research study, and have received sufficient information regarding the nature, aims and risks of the study.

☐ I understand that my participation is voluntary, and I am able to leave the interview at any time without having to provide a reason.

☐ I understand that if I decide I no longer wish to participate in the study, I can withdraw my data up to one month following participation without having to provide a reason.

☐ I understand that if I decide to withdraw from the study, I will still receive the University course credit/entry into the prize draw for the £50 Amazon voucher.

☐ I understand that the interview will be recorded and transcribed, and that direct quotes may be included in the written report.

☐ I understand that all information I provide will remain anonymous and be kept confidential by the principal investigator.

☐ I give my full consent to participate in the research study described in the information sheet.

Participant name: **Date:**

Participant signature:

I can confirm that I have explained the details of this research study, as outlined in the information sheet, to the participant, and believe their consent to participate is based on a clear understanding.

Researcher name: **Date:**
Researcher signature:

Appendix D: Participant Debrief

Debrief Sheet

Thank you for taking the time to participate in this study, your involvement is very much appreciated.

What the study involved:

This study involved taking part in an interview to discuss the future care planning process for your sibling with learning disabilities. Whilst siblings of individuals with learning disabilities are adopting an increasing role in the future care of their brothers and sisters, much of the available research literature indicates that parents often avoid open family discussions regarding future planning. Moreover, in families where these conversations do occur, sibling involvement is often limited to topics concerning financial arrangements and guardianships. The limited involvement of siblings can result in difficulties within family relationships and increased stress for all parties.

As a result of this research evidence, the current study aims to gain a better understanding of how future planning is talked about, and constructed within the family. An increased understanding of this process may better enable professionals to initiate or facilitate such conversations, and as such, it is hoped that the study's findings may help inform professional guidelines and clinical practice.

Should participation have caused any distress:

It is acknowledged that the interview topic may have been difficult to talk or think about. Therefore, should your participation in the study have caused any distress, please inform the Principal Investigator and/or contact your GP. You may also find it helpful to contact one or more of the following organisations for support or advice:

MIND: 0300 123 3933
www.mind.org.uk

Samaritans: 116 123
www.samaritans.org

CONTACT: 0808 808 3555
www.contact.org.uk

SIBS:www.sibs.org.uk

What happens with the data now:

The interviews will now be transcribed and analysed using discourse analysis. Both the audio recording and the written transcripts will be stored in a secure place, and subsequently destroyed at the end of my studies in September 2019. The data you have provided will be made anonymous, and it will therefore not be possible to trace any information back to you.

Should you have any questions regarding the study, or if would like for your data to be removed, please contact the researcher using the details provided below. You may also wish to request a summary of the study's findings, which will be provided once the research is completed.

Thank you again for participating in this research study.

Contact details of Principal Investigator:

Bronwen Royall
Doctoral Student in Clinical Psychology
University of Exeter
Email: br300@exeter.ac.uk
Telephone: 07714255521

Appendix E: Interview Schedule

Interview schedule

Title of study: Future planning for individuals with learning disabilities: Hearing the voices of siblings

Thank you for volunteering to participate in this interview. The interview aims to discuss the process of planning the future care of [sibling name] within your family. The interview questions are rather broad, affording an opportunity for us to have an open and collaborative discussion about your experiences, and enabling you to discuss the things which you consider to be highly relevant/ important when thinking about this topic.

Do you have any questions before we begin?

1. Can you tell me a bit about your current involvement in [sibling name] life/care?
    - What does your involvement/role look like?
    - How did you develop this role?
    - How do you feel about your involvement?
2. What is your current understanding of any future plans for [sibling name]?
    - How have these plans been developed?
    - What are your views on these plans?
3. How are future plans discussed within your family?
    - How are future plans decided?
    - What is it like talking about the future with your family?
    - What is your role within the future planning process?
4. What are the benefits associated with planning [sibling name] future care?
5. What are the difficulties associated with planning [sibling name] future care?
6. What do you think about your role in your [sibling name] future?
    - What does your family think about your role in your sibling’s future?

Appendix F: Dissemination Statement

It is intended for the results of this study to be disseminated to various parties, as outlined below.

Dissemination to Participants

The twelve siblings that participated in the research study will be sent a summary of the findings via email. They will also be invited to request a copy of the complete write-up, should this be of interest.

Dissemination to Professionals

The research findings were presented to the South West Learning Disability Special Interest Group conference on 27 March 2019. The conference was attended by Clinical Psychologists, Trainee Clinical Psychologists and Assistant Psychologists working in various Learning Disability Support Services (NHS and private) across the South West of England. Several professionals requested a summary of the research findings, which will be sent following submission.

Submission for Journal Publication

It is intended for the study to be submitted for publication to the British Journal of Learning Disabilities.

Appendix G: Author Guidelines for British Journal of Learning Disabilities

Author Guidelines

INSTRUCTIONS FOR AUTHORS

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.

1. GENERAL

Aims and Scope

British Journal of Learning Disabilities is an interdisciplinary international peer-reviewed journal which aims to be the leading journal in the learning disability field. It is the official Journal of the British Institute of Learning Disabilities. It encompasses contemporary debate/s and developments in research, policy and practice that are relevant to the field of learning disabilities. It publishes original refereed papers, regular special issues giving comprehensive coverage to specific subject areas, and especially commissioned keynote reviews on major topics. In addition there are reviews of books and training materials, and a letters section. The focus of the journal is on practical issues, with current debates and research reports. Topics covered could include, but not be limited to:

- Current trends in residential and day-care services
- Inclusion, rehabilitation and quality of life
- Education and training
- Historical and inclusive pieces [particularly welcomed are those co - written with people with learning disabilities]
- Therapies
- Mental health issues
- Employment and occupation
- Recreation and leisure
- Ethical issues, advocacy and rights
- Family and carers
- Health issues
- Adoption and fostering
- Causation and management of specific syndrome
- Staff training
- New technology
- Policy critique and impact

Its readership is wide comprising members from the British Institute of Learning Disabilities, as well as academics, family carers, practitioners, staff in health and social care organisations, as well as a wide range of others with a personal and professional interest in learning disability, and who wish to promote enriched lifestyles, as well as high quality services and support for adults and children with learning disabilities.

The *British Journal of Learning Disabilities* crosses all professional groups and all academic disciplines concerned with learning disability. The opinions expressed in articles, whether editorials or otherwise, do not necessarily represent the official view of the British Institute of Learning Disabilities and the Institute accepts no responsibility for the quality of goods or services advertised.

Please read the instructions below for brief details on the Journal's requirements for manuscripts. Please visit the Journal website:

http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3156 for full and updated Author Guidelines and Wiley-Blackwell Publishing's Author Services website, **http://authorservices.wiley.com/bauthor**, for further information on the preparation and submission of articles and figures. Manuscripts in an incorrect format may be returned to the author.

Please note that we also welcome articles by or with people with learning disabilities.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Papers based on original research involving people with learning disabilities must include an ethical statement to confirm either that the research has received formal ethical approval from an appropriate ethics committee or that the research has taken appropriate steps with regard access, informed consent, confidentiality and anonymity. **Contributors to the article other than the authors accredited should be listed under an Acknowledgements section which should also include, if appropriate, details of any potential conflict of interests.**

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Authors will be required to sign a Copyright Transfer Agreement (CTA) for all papers accepted for publication. Signature of the CTA is a condition of publication and papers will NOT be published unless a signed form has been received. After submission authors will retain the right to publish their paper in various media/circumstances (please see the CTA for further details).
If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:
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If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):
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3. SUBMISSION OF MANUSCRIPTS

*The British Journal of Learning Disabilities has now adopted ScholarOne Manuscripts (formerly known as***Manuscript Central)***, for online manuscript submission and peer review. The new system brings with it a whole host of benefits including:*

- *Quick and easy submission*
- *Administration centralised and reduced*
- *Significant decrease in peer review times*

From now on all submissions to the journal must be submitted online at **http://mc.manuscriptcentral.com/BLD**. Full instructions and support are available on the site and a user ID and password can be obtained on the first visit. If you require assistance then click the Get Help Now link which appears at the top right of every Manuscript Central page. If you cannot submit online, please contact Christian Mañebo in the Editorial Office by e-mail **BLDedoffice@wiley.com**.

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- Launch your web browser (supported browsers include Internet Explorer 6 or higher, Netscape 7.0, 7.1, or 7.2, Safara 1.2.4, or Firefox 1.0.4) and go to the journal's online Submission Site: http://mc.manuscriptcentral.com/BLD
- Log-in or click the 'Create Account' option if you are a first-time user.

- 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'.
- 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/BLD and enter your e-mail address. The system will send you an automatic user ID and a new temporary password.
- Log-in and select 'Author Center'.

3.2. Submitting Your Manuscript

- After you have logged in, click the 'submit a Manuscript' link in the menu bar.
- 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.
- Click the 'Next' button on each screen to save your work and advance to the next screen.
- 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.
- Review your submission (in HTML and PDF format) before sending to the Journal.
- Click the 'Submit' button when you are finished reviewing.

Data Protection

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at **https://authorservices.wiley.com/statements/data-protection-policy.html**

3.3. Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) 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, accessible summary, summary, text, references, tables, and figure legends, but *no* embedded figures. Figure tags should be included in the file. Manuscripts should be formatted as described in the Author Guidelines below.

3.4. 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.

3.5. E-mail Confirmation of Submission

After submission you will receive an e-mail to confirm receipt of your manuscript. If you do not received 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.

3.6. Manuscript Status

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

4. MANUSCRIPT FORMAT AND STRUCTURE

All manuscripts submitted to British Journal of Learning Disabilities should include: Accessible Summary, Keywords, Abstract, Main Text (divided by appropriate sub headings) and References. Manuscripts should not be more than 5,000 words in length including references.

Title Page: This should include: a short title to indicate content with a sub-title if necessary; the full names of all the authors; the name(s) and address(es) of the institution(s) at which the work was carried out (the present addresses of the authors, if different from the above, should appear in a footnote); the name, address, telephone and fax numbers, and email addresses of the author to whom all correspondence and proofs should be sent; a suggested running title of not more than 50 characters, including spaces should be provided in the header of each page.

Accessible Summary: As well as an abstract, authors must include an easy-to-read summary of their papers. This was introduced in 2005, and was done so in the spirit of making research findings more accessible to people with learning disabilities. The editorial board also believe that this will make ‘scanning’ the Journal contents easier for all readers. Authors are required to:

- Summarise the content of their paper using bullet points (3 or 4 at most),
- Express their ideas in this summary using straightforward language, and

- State simply why the research is important, and should matter to people with learning disabilities.

Keywords: these are words which have relevance to the type of paper being submitted, this is for reviewing and citing purposes. You are asked by Manuscript Central to input keywords when submitting a paper, but up to 6 keywords must also be included within the 'main document' underneath the Accessible Summary.

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Main Text: The text should then proceed through sections of Background/Introduction, Review of Literature, Research Questions/Hypotheses, Materials, Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style

Abbreviations and symbols:

All symbols and abbreviations should be clearly explained. Abbreviations should not be used when they refer to people (e.g. learning disabilities, not LD; developmental disabilities, not DD; intellectual disabilities, not ID). Please also use “people with learning disabilities” wherever possible, not “learning disabled people”.

References: APA – American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

Journal article:

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. The American Journal of Psychiatry, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. Brain, 126(4), 841–865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., … Carroll, J. (2004). Sex differences in developmental reading disability: New findings from 4 epidemiological studies. Journal of the American Medical Association, 291(16), 2007–2012. doi: 10.1001/jama.291.16.2007

Book edition:

Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

References should refer only to material listed within the text.

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