

How do Carers of People With an Intellectual Disability With Dementia Experience Their Role and the Support They Receive Through Services?

Submitted by

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to the University of Exeter

as a thesis for the degree of Doctor of Clinical Psychology

in May 2014

Supervised by Dr Phil Yates

Word Count: 11,955

Title of nominated journal: Journal of Intellectual Disability Research

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A Literature Review of the Experiences of Family
Carers for People With an Intellectual Disability, as
Revealed Through Qualitative Research

Submitted by

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in May 2014

Supervised by Dr Phil Yates

Word Count: 3957

Title of nominated journal: Journal of Intellectual Disability Research

Abstract

Background

People with an intellectual disability often have a range of impairments that requires them to access support. Family carers assist people with intellectual disabilities and past research has investigated these carers' perspectives using qualitative methodologies. Research into this area represents a significant need in the community and by health professionals, that of attempting to understand family carers' unique experiences and to investigate how best to support this group who provide fundamental support to people with intellectual disabilities.

Method

This literature review utilised a qualitative systematic reviewing methodology, ENTREQ to search online journal databases (PsycINFO, Science Direct, and Web of Science), and presents a summary of the published qualitative research that investigates the experiences of family carers for people with intellectual disabilities.

Results

The literature search of the online databases yielded a total of 739 articles. The article titles and abstracts were assessed as to whether they met inclusion criteria and a total of 24 full articles were retrieved. The reviewer then assessed the 24 papers for eligibility which resulted in 12 papers being included in the review.

Conclusions

The findings from the 12 studies in the review were summarised as 6 main themes: *experiences of symptoms and diagnosis; difficulties for carers; sources of support and carer coping strategies; suggestions for improving services; people with an intellectual disability and their carers having different*

perspectives; and *concerns about the future*. Limitations and suggestions for future research are discussed.

Keywords: Literature review, systematic review, family carer, intellectual disability, learning disability, qualitative.

A Literature Review of the Experiences of Family Carers for People With an Intellectual Disability, as Revealed Through Qualitative Research

Rationale

People with an intellectual disability (ID) often have delayed or abnormal early development, a range of intellectual and functional difficulties, and experience these impairments into their later lives (Holland, 2000). As a result of these impairments many people with IDs require support with health, communication, accessing services, learning, and to help them achieve an improved quality of life (Hubert & Hollins, 2000). In addition, many who require support because they have a disability or are ill are supported by carers who are family, partners, or friends (Carers UK, 2012). This literature suggests that family carers provide a unique type of support for their relatives, alleviating a large financial burden on society, and offering continuity of support for the person they are caring for over many years. An important factor in services supporting people with an ID is to understand carers' perspectives and to draw on their insights into how best to support them and the people they care for.

This review describes a literature search of studies that investigated the experiences of family carers for people with an ID, as revealed through qualitative methodologies. The aim is to contribute to a better understanding of the literature on family carers' experiences, their views on their roles, common themes across studies, the services they use, and their experiences of those services. This review will contribute to knowledge and practice in an area that represents a need in the community: to understand family carers' unique experiences and to investigate how best to support those who provide fundamental help to people who have IDs.

This review utilised systematic reviewing guidelines in order to explore relevant literature related to specified research questions (Tong, Flemming, McInnes, Oliver, & Craig, 2012). The review sets out to investigate the experiences and perspectives of carers for people with an ID, to try and understand what themes are common across these different qualitative studies, and to suggest areas for future research.

Research Questions and Aims

What are the experiences of family carers for people with an intellectual disability, as revealed through qualitative research? In order to answer this research question the following aims are presented:

1. To systematically search for published qualitative research investigating the experiences of family carers for people with an intellectual disability.
2. To summarise this previous research through presenting the studies and types of participants, methods used, and key findings.
3. To discuss common themes across these studies.
4. To present possible areas for future research.

Method

Approach to Searching

The search used a preplanned search strategy to seek all available studies in the area under review (Tong et al., 2012). The literature search utilised systematic reviewing methodology guidelines specifically for qualitative research (Tong et al., 2012). Systematic reviews use systematic methods to search relevant literature, minimise any potential bias in selection of articles, set out specific search criteria and inclusion criteria, and to answer a research question (Green et al., 2011). The review followed the ENTREQ (enhancing

transparency in reporting the synthesis of qualitative research) statement guidelines (Tong et al., 2012). The ENTREQ statement is a checklist of 21 items that provides guidance on reporting reviews of qualitative research. The items are grouped into five main areas and include guidance on the introduction, method and methodology, the literature search and selection of papers, the appraisal of the selected papers, and the synthesis of the papers' findings (Tong et al., 2012). While the current review did not produce a meta-analysis and instead reported common themes across studies, the review did follow the ENTREQ guidelines in structuring the review.

Inclusion Criteria and Rationale for Selecting Studies

The inclusion criteria for selection of literature were:

1. Published studies in journals (non published articles such as dissertations or papers submitted for publication were omitted in order to review only those articles whose methodologies were of a high enough standard to be peer reviewed) and only original studies (systematic reviews and meta-analysis articles were not included).
2. Only articles written in English (articles in languages other than English were excluded).
3. Studies that use qualitative methodologies (qualitative methods are well suited to capturing subjective perspectives of peoples' experiences [Kazdin, 2003]).
4. Types of participants:
 - a) family carers for people with an ID (only family carers were included to capture the unique experiences of family members as opposed to experiences of nurses or care home staff)

- b) carers over 18 years old (where participants are required to be of legal consenting age).
5. Only studies where a focus of the study is on the experiences of carers for people with an ID.
 6. Only studies where the person's ID is a primary and not secondary focus, such as papers being omitted when the focus was on the experience of diabetes for people with an ID.
 7. Timescale for published studies was not limited from any specific publication year (all years were searched in order to ensure that no older published papers were omitted) up until August 2014.

Data Sources and Electronic Search Strategy

In August 2014 online databases were searched to identify qualitative studies that investigated experiences of family carers for people who have an ID. Three search engine databases were used in the literature search in order to form a comprehensive search of relevant articles. These search engines were PsycINFO, Science Direct, and Web of Science.

In defining search terms there should not be too many different terms, but there must be a wide variety of combinations with other terms and within the same concepts (Higgins & Green, 2008), such that for example the concept of ID is searched for using other relevant variations including learning disability. It is important when choosing keywords for the online search to familiarise oneself with the differing terminology and keywords being used across the literature and in the different search engines (Wu, Aylward, Roberts, & Evans, 2012). Therefore, the reviewer read through a selection of papers from an initial database search to assess what differing keywords were used. In addition, some of the database search engines, such as Web of Science, include the

facility to find alternative forms of search terms and this was utilised when the databases had this capability. The keywords used to search the databases were “carer” (and the variation “caregiver”) and “intellectual disability” (and the variations “learning disability” and “mental retardation”). Although only qualitative studies of family carers were included in the review these terms were not included as keywords in the database searches. The terms “qualitative” and “family” have several similar terms that may have featured in the papers and qualitative papers do not always include the term qualitative in their title and abstract. Therefore, the terms qualitative and family were not included in the engine search in order to ensure that the reviewer did not omit any potentially relevant articles. In addition to the electronic search, the reviewer also read articles identified from relevant articles’ reference lists and additional papers from electronic searches for related fields of research.

Study Screening Methods

Once the online databases were searched the duplicate studies were identified and removed (see Figure 1). The reviewer read the titles of the papers and those titles that were not related to the topic were excluded. When the titles were identified as either potentially relevant or ambiguous the reviewer read the abstracts to determine whether they met the review’s inclusion criteria. Abstracts that met the inclusion criteria were identified and search engines and the internet were searched to collect the full articles. The reviewer then read and recorded whether these full papers met the inclusion criteria. Data from the relevant full articles were then extracted and included information on the author, year of publication, aim or research question, participants, method and measures used, analysis method, and findings or themes (see Table 1). Themes from the articles were then compared across the studies.

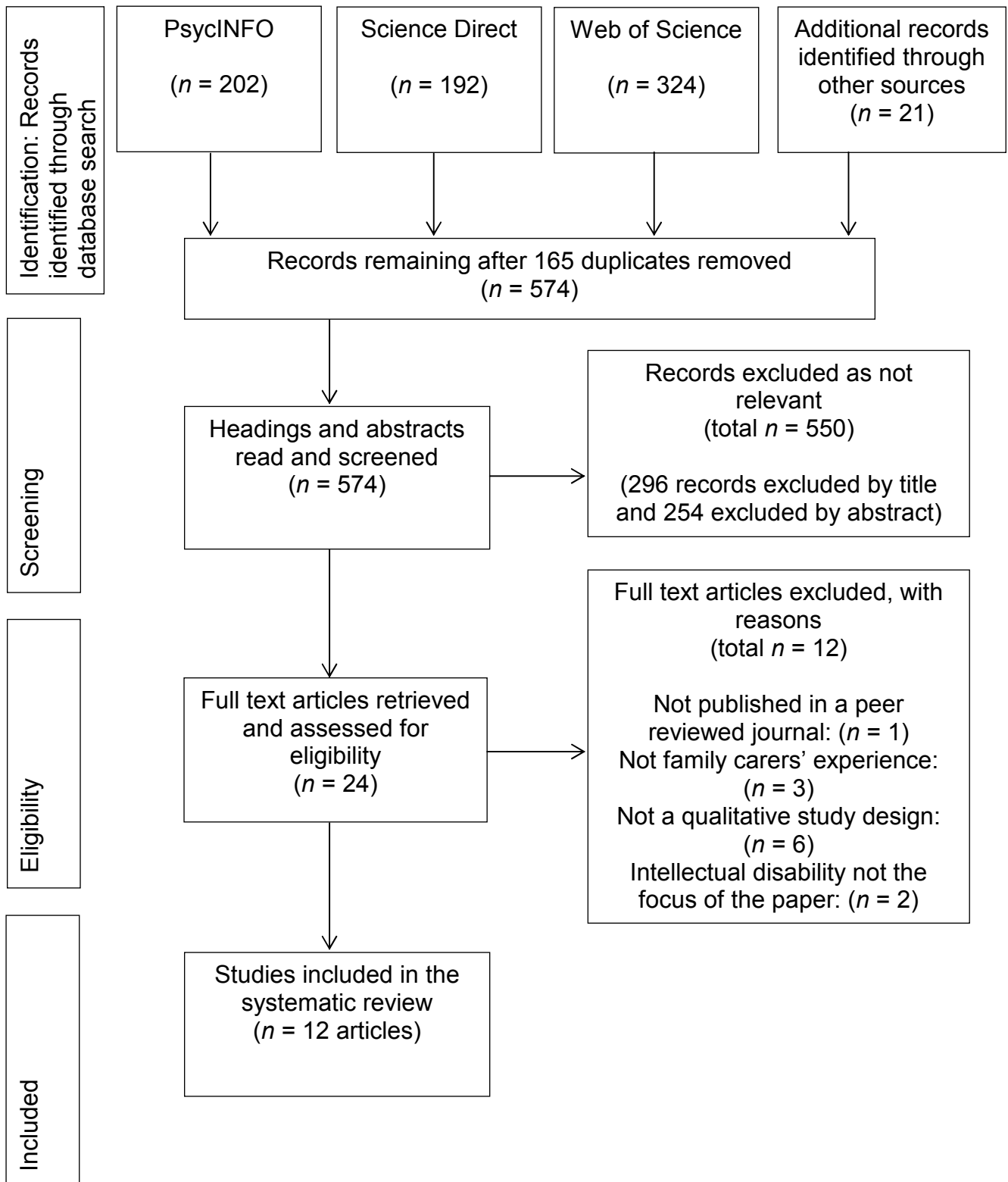


Figure 1. Selection process of articles using the PRISMA flowchart (Moher, Liberati, Tetzlaff, & Altman, 2009). The PRISMA (preferred reporting items for systematic reviews and meta-analyses) flowchart shows the search strategy and selection of articles in the review.

Results

Study Selection and Characteristics

The literature search of the online databases yielded a total of 739 articles including 202 articles in PsycINFO, 192 articles in Science Direct, and 324 articles in Web of Science (see Figure 1 for literature search PRISMA flowchart). The reviewer identified 21 additional articles for the screening process through hand searching reference lists and from carrying out other literature searches in the area of carers and intellectual disabilities. Once all of the duplicates were removed the article titles and abstracts were assessed as to whether they met inclusion criteria. A total of 24 abstracts and titles met the reviews' inclusion criteria and the full articles were retrieved. The reviewer then assessed the 24 papers for eligibility which resulted in 12 papers being excluded (see Figure 1 for reasons for papers being excluded) and 12 articles included in the final systematic review. Table 1 presents a summary of the articles included in the systematic review. The primary reason only 12 articles out of 574 articles met the inclusion criteria of the review was that the online databases search did not screen for only qualitative studies or for only family carers. This exclusion of articles was not applied during the initial stage in the search process. This approach was taken in order to not miss any potentially relevant papers but it did therefore yield a large amount of papers to process for eligibility for the review.

Table 1

Overview of Papers Included in the Review to Answer the Research Question: What Are the Experiences of Family Carers for People With an Intellectual Disability, as Revealed Through Qualitative Research?

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
Deb, Hare, & Prior, 2007, UK	“The qualitative interviews served to gather information on the individual family carer’s perception and assessment of behavioural changes in an adult with DS since the onset of dementia” (p. 728).	24	Carers of people with Down’s syndrome and dementia	Open-ended semistructured one-to-one interviews and focus groups to clarify terms of reference	Concordance computer programme that identified the most frequent terms and a qualitative software data analysis package “NUDI*ST”	The study identified the following themes as behavioural changes in the person with Down’s syndrome and dementia that the carer has identified: Forgetfulness/memory problems, confusion, problem with instructions, slowness, speech and language problems, sleep problems, loss of skills, problems with socializing, lack of confidence, loss of interest, obsessive symptoms, balance problems, emotional problems, hallucinations and illusions, covering up for loss of memory, hypochondriasis , and change in personality.
Ferguson, Jarrett, &	”This research explored the	13	Paid and unpaid	Semistructured one-to-one	Thematic content	“We found that carers and healthcare staff need support to understand how difficult it can

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
Terras, 2010, UK	choice-making experiences of ... [those] with learning disabilities (<i>N</i> = 4) and/or their primary carer (<i>N</i> = 13)" (p. 73).		carers for people with an intellectual disability	interviews	analysis ¹	be to make choices, and how they can help people with a learning disability to make choices "(p. 73). "Inclusion and choice making. Feelings, attitudes and roles and responsibilities in supporting choice. Knowledge and understanding of hydrotherapy. Factor impacting on attendance at healthcare appointments" (p.77).
Johnson, O'Reilly, & Vostanis, 2006, UK	"This study sought to understand how parents cope and adapt to the care of children with learning disability and problem behaviours" (p. 190).	18	Family carers for children (aged five to 15 years) with an intellectual disability and severe problem	Semistructured interviews	Grounded theory	"The data were analysed using grounded theory techniques which identified 'secondary stressors' for the parent. These were social isolation, conflict, limitation of lifestyle and self-blame. It is proposed that the amalgamated impact of these can weaken parents' coping resources and, therefore, may prove to be as significant to the negative association with maternal wellbeing as the problem behaviour" (p. 188).

Author, year, country	Aims or research questions	No. participants	Participants behaviours	Method and measures	Analytical technique	Outcomes and themes
Kenny & McGilloway, 2007, Ireland	“This study describes and analyses the nature and consequences of care and coping among parents of children (<16) with learning disabilities living in the Greater Dublin area” (p. 221).	32	Parents of children (<16) with learning disabilities	Open-ended questions	Thematic analysis	Parent carers discussed many factors involved in caring including their “need for effective and appropriate service provision... [, that some were] suffering more than others, although many appear to have benefited from the ‘buffering’ effect of the support provided by their spouses/ partners and families...[, and] that more than three-quarters of the participants in the current study were receiving support from other parents may have been beneficial,... [and that] participants were clearly exposed to a range of well known potential stressors such as employment outside the home, difficulties in dealing with social and practical care tasks, uncertainty surrounding the future care of their child and feelings of restriction on their everyday lives” (p. 226).

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
Mansell & Wilson, 2010, UK	“The aim of this article is to report findings from a study that asked carers for their views on a wide range of topics... [including] issues of	15	Parents or Informal carers for people with an intellectual disability	Focus groups with an interview schedule based on data collected from questionnaires	Analysis method not named but described as an approach of using codes and identifying emerging	<p>“Participants employed both emotion- and problem focused coping strategies to help them manage their caring... [,] appeared to have a realistic outlook of their child’s disability and sought information about their condition, both of which have been shown to be effective coping strategies” (p. 226).</p> <p>“The lack of appropriate information for parents from the initial diagnosis and beyond, is alarming and something that should be tackled at grass-roots level” (p. 226).</p> <p>“Issues of concern to carers included access to health and social care information and services; quality and quantity of respite care; suitable educational provision; independence and quality of life (for a person with learning disability); and what would happen to the person with learning disability when the carer was no longer able to carry out their</p>

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
	concern to carers” (p. 21).				categories to develop themes	“caring role” (p. 21).
Power, 2008, Ireland	“The aim of this article is to examine the experiences of families with young adults with learning disabilities trying to access services” (p. 92).	25	Family carers for people between 18 and 30 with an intellectual disability	Semistructured interview	Grounded theory	“The findings show that there is limited flexibility, choice and availability in meeting the preferences of the service-users, and throughout the study, services were characterised as being non-supportive interactions” (p.92).
Prosser, 1997, UK	“The object of this paper, therefore, is to elaborate on the previous paper by (1) examining the extent of financial	32	Primary carers of adults with an intellectual disability	Survey and semistructured interview	Coding responses and using content analysis	“Results indicated that plans for the future residential care were minimal. Only 28% of carers had made any concrete plans for future residential care of their relative. In the majority of cases, carers were committed to maintaining long-term home care for their

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
	and residential care plans and preparations carers have made; (2) eliciting carers' expectations and preferences regarding the future care of their relative; and (3) identifying factors influencing carers' decisions to undertake future care planning" (p. 18).		aged over 40. Interviews conducted at carer's home			relative with intellectual disability for as long as possible. Attention is drawn to the significant number of elderly parental carers (82% of this sample) who have not made concrete future residential arrangements. Carers were more likely to establish financial plans than residential plans for their family member. No clear differences were found between carers to indicate factors influencing whether they had made preparations for the future. Explanations for the reluctance of carers to plan for the future were, therefore, explored. The overall conclusion to be drawn from the research is that 'crisis' resettlement due to ill health or death of the main carer is highly likely. The potential role of service-providers is briefly discussed" (p. 15).
Taggart, Truesdale-	"The overall aim of this study was to	19	Family carers for	Semistructured interviews	Thematic content	"Four main themes were identified around future planning: unremitting apprehension,

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
Kennedy, Ryan, & McConkey, 2012, UK	examine the support needs of ageing family carers in developing future plans for a relative with an intellectual disability” (p. 220).		people with an intellectual disability		analysis that used Braun and Clarke’s (2006) approach	the extent of planning, obstacles encountered and solutions for future planning. Avoidance, lack of guidance and a lack of appropriate residential provision were cited as obstacles to making future plans compounded by the emotional upset experienced by carers in thinking about the future” (p. 218).
Viecili, Lunsky, & Strike, 2009, Canada	“Caregiver and client perspectives on what is important in the lives of adults with intellectual disabilities were examined. A qualitative analysis of the differences between what is	92	Carers and people with a an intellectual disability	Set questions interview with caregiver and person with an intellectual disability	Thematic analysis	“When responses of the two groups were compared, no agreement was found for 44% of the cases. Some agreement was found for 39% of the cases and strong agreement was found for 17% of client/caregiver dyads. The priority areas of the two groups differed, with clients prioritizing Family and Friends and Recreational Activities and caregivers prioritizing Health and Safety and Self-Determination” (p. 99).

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
	important to individuals with intellectual disability and what others [caregivers] think is important for them was conducted” (p. 99).					
Weeks, Nilsson, Bryanton, & Kozma, 2008, Canada	“In this study, we utilized both qualitative and quantitative methods to explore (1) the key issues that older parents of sons and daughters with ID are currently facing, and (2) the parent’s	43	10 parents in pilot interviews used for the qualitative component of the study and 33 parents in in-depth interviews	Pilot interviews using open-ended questions and in-depth face-to-face interviews	Thematic analysis	“Analysis of qualitative data resulted in the following five themes: (1) worry about the future care of son or daughter; (2) concern about services funding; (3) having housing and care options; (4) lack of provider understanding of carer’s needs; and (5) helping son or daughter become a productive and active member of society” (p. 180).

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
	preferences for housing and care options for their sons and daughters in the future” (p. 181).		used for quantitative analyses			
Wodehouse & McGill, 2009, UK	“This study, therefore, asks two related questions: What problems do parents identify in the support they have received [through services]? How could that support have been more helpful?” (p. 646).	13	Mothers of children between 7 and 17 years who have a an intellectual disability and challenging behaviour	Semistructured pilot interviews ($n = 2$ interviews) conducted within participants homes	Interpretative phenomenological analysis (IPA)	“Parents reported problems with generic disability services including accessing good services, obtaining relevant information, working relationships with professionals and issues with respite provision. Concerns were also expressed about challenging behaviour-specific provision including ineffective strategies being suggested, an apparent lack of expertise, insufficient input and their child’s exclusion from services” (p. 644).

Author, year, country	Aims or research questions	No. participants	Participants	Method and measures	Analytical technique	Outcomes and themes
Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004, Australia	“The aim was to better understand the factors that have an impact upon the success of communication in a medical consultation [between GPs, people with intellectual disabilities, advocates, and carers]” (p. 212).	7 carers and 2 advocates	Carers and advocates for people with an intellectual disability	Semistructured interview	Thematic analysis	“Carers were strong advocates for the person with intellectual disability, but indicated insufficient skill and knowledge to provide the level of assistance required in the consultation” (p. 212). “This qualitative study has proposed a conceptual model, which proposes attention to training, access, adequate preparation, and shared information to guide better communication between doctor, patient and carer. Support workers were urged to encourage people with intellectual disability to go to the same GP all the time and to get to know them well” (p. 224).

Note. 1 = the authors have used differing terminology but the method is considered to mean the same as “thematic analysis”. No. = number. DS = Down’s syndrome. GP = general practitioner.

The studies reviewed focused on a range of experiences by carers including their use of services, their stressors, decision making, disorder related symptoms of the person with an ID that they care for, and planning for the future. While one article was published in 1997 the rest of the papers were from the past 10 years, with the most recent published in 2012. The papers in the review are relatively recently published and this may reflect a growing recognition of the importance of this area of research in recent years. The amount of participants in the studies ranged from seven to 92 participants. While it is a strength of some of the studies that included larger sample sizes as these studies were able to gain perspectives from a wider group of people, some of the studies that included smaller sample sizes, such as Taggart et al. (2012) and Mansell and Wilson (2010), were still able to produce coherent and informative themes.

Concepts and Definitions

While some studies in the review defined key terms, such as the Power (2008) paper defining learning disability, most articles chose not to define terms like intellectual disability or learning disability. Those papers that did not define these terms may have judged that the DSM-IV definition of ID is a widely accepted definition of the disorder (APA, 2000). However, Power (2008) explains that while the term can generally be defined as long-term impairments in social functioning and intelligence there are difficulties with defining the disorder. Issues such as the varieties of different types of ID, such as Down's syndrome or autism, being defined by the same general term can complicate communication across different professionals, family members, and research studies.

The term intellectual disability was used across most of the studies in the review. Those studies conducted in the UK or Ireland tended to use the term learning disability (see Table 1). The term carer was used in the majority of studies and the terms carer, parents, and caregiver tended to be used interchangeably within and across studies. The use of similar terms across different studies is a strength of this area of research as it allows for a shared understanding across different research disciplines and different countries. However, it must be acknowledged that these terms were used for the current literature search and there may be alternative terms referring to carers or people with an ID, that are used in other studies that would therefore not have been retrieved in this search.

Research Methodologies

The majority of studies in the review used semistructured interviewing methodologies to collect data. Seven studies used semistructured interviews, two studies used open-ended questions, one study used a set questions interview, and two interviews included focus groups in their data collection. Most studies acknowledged the strengths of using a flexible form of interviewing that allowed interviewers to explore themes and areas of interest. The studies used a variety of data analysis methods. Six studies used thematic analysis, two studies used grounded theory, one study used interpretative phenomenological analysis (IPA), one study described its analytical approach as using codes and identifying emerging categories to develop themes, one study used a qualitative software data analysis package, and one study coded responses and used content analysis. While the studies used a range of analytic methods they did produce themes or patterns in carers' experiences that can provide a basis for cross-study comparison.

Conclusions/Findings

Many of the studies in the review investigated carers' perceptions about the future and what will happen to the person they care for later in their lives. These worries included concerns about funding to services in the future, future housing and care options, uncertainty that services may not understand the carers' needs in the future (Weeks et al., 2008), that there were behavioural changes following the diagnosis of dementia for the person with an ID (Deb et al., 2007), and that carers tend to not make plans for future residential care which made unplanned resettlement of the person cared for increasingly likely (Prosser, 1997). These studies' areas of focus reflect the growing number of people with an ID who are living past the age of their caregivers and the increased vulnerability this group has to other difficulties as they age, such as dementia. In addition, the studies also show that many carers are not confident that the person they care for with an ID will be supported in the future.

Carers' experiences of services were the focus of many studies where services were perceived as inflexible and many of the interactions to be non supportive (Power, 2008). Other studies reported that carers had problems with accessing good services, with obtaining appropriate information, with their relationships with professionals, and issues with the provision of respite support (Wodehouse & McGill, 2009). Suggestions for improving service user interactions were suggested where people with an ID were encouraged to see the same GP and to build that relationship over time (Ziviani et al., 2004).

Discussion

Critical Evaluation of Findings

The 12 studies in the review produced a number of findings related to carers' experiences and can be summarised as six main themes.

Experiences of symptoms and diagnosis. People with IDs and dementia presented with similar symptoms to people with just dementia (Deb et al., 2007) and carers reported that not enough information was provided during the process of diagnosing IDs (Kenny & McGilloway, 2007).

Difficulties for carers. Carers reported experiencing a range of stressors including difficulties with practical caring tasks, experiencing restrictions in their daily lives (Kenny & McGilloway, 2007), concerns about respite care (Mansell & Wilson, 2010; Wodehouse & McGill, 2009), feeling they had insufficient knowledge at times (Ziviani et al., 2004), and that stressors such as social isolation and self-blame can weaken carers' coping resources (Johnson et al., 2006). Regarding services, carers reported difficulties with accessing information and services (Mansell & Wilson, 2010; Wodehouse & McGill, 2009), that services for people with challenging behaviour lacked expertise and effective strategies (Wodehouse & McGill, 2009), and that services were found to have a lack of understanding about carers' needs and to be non supportive (Power, 2008; Weeks et al., 2008).

Sources of support and carer coping strategies. Carers had a range of sources of support, including family members, and other carers reported using an array of coping strategies that included problem focused strategies, emotion focused strategies, accessing relevant information, and being realistic about the person's disability (Kenny & McGilloway, 2007).

Suggestions for improving services. Carers reported that services should work to increase carers' knowledge so that they could help to encourage people with an ID to make decisions, be productive, and to increase their independence and quality of life (Ferguson et al., 2010; Mansell & Wilson, 2010; Vecili et al., 2009; Weeks et al., 2008). Carers stressed the importance

of strong relationships and good communication between doctors, people with an ID, and carers (Ziviani et al., 2004).

People with an ID and their carers having different perspectives.

Comparisons of what people with IDs and their carers feel is important showed that both groups only agreed with each other just over half the time. A main difference in perspectives was that carers prioritised self-determination and health and safety for the person with an ID, while people with IDs prioritised family, friends, and recreational activities (Viecili et al., 2009).

Concerns about the future. Carers experienced a large amount of uncertainty over the future and what would happen to the person when the carer could no longer carry out their role (Kenny & McGilloway, 2007; Mansell & Wilson, 2010; Weeks et al., 2008). Carers tended to not make future plans for themselves or the person they care for and therefore unplanned resettlement of the carer and person cared for was likely in later life (Prosser, 1997).

A possible reason for carers not planning for the future was suggested by Taggart et al.'s (2012) study that found that carers were avoidant, lacked guidance, and were emotionally upset about thinking and planning for the future. The studies in the review indicated that despite the negative consequences of not making plans for the future, family carers still tended to avoid making plans and found the process emotionally difficult. A theory that could explain this avoidance is the learned helplessness model. Abramson, Seligman, and Teasdale (1978) describe the learned helplessness theory as a process of what follows when a person learns that an outcome is relatively uncontrollable. The person can be impacted in three main ways: decreasing their motivation; deficits in their cognitions; and emotional difficulties. Applying the theory to carers' difficulties with planning for the future, the theory would

suggest that carers' awareness of the increased likelihood of the person with ID developing dementia, and other difficulties, may reinforce carers' beliefs that there will be an inevitable decline in the person they care for. The carers then develop a lack of motivation to plan for the future. In addition, the carers themselves are more likely to develop emotional difficulties over time, such as depression, as a result of recognising the limited control they have over the long term outcomes of those they care for (Abramson et al., 1978).

Gaps in Existing Knowledge

People with an ID are now living significantly longer than before (Hubert & Hollins, 2000). Due to people with an ID developing dementia earlier in life and in far greater numbers than in the general population (Prasher, 1995), there is a growing need to understand this phenomenon. An important factor in understanding people with an ID and dementia is to investigate the experiences of their carers who contribute to relieving a significant burden that would otherwise be placed on limited NHS resources. However, the current literature review identified only the Deb et al. (2007) study that focused on carers for people with an ID and dementia. This suggests that there is a lack of existing knowledge on the specific experiences of these carers. This area of research requires studies using qualitative and quantitative methodologies to identify mechanisms that could provide services with information to assist carers with their role and to help improve their quality of life.

Some studies in the review could have included more information on why some carers chose not to participate, such as in the Weeks et al. (2008) study where three people chose not to take part in the pilot study but no reason was provided. Efforts should be made to gather this data as it can contribute to our

understanding of how best to maximize participation and could help services to be more supportive and sensitive to participants needs.

Limitations of the Review

The ENTREQ statement (Tong et al., 2012) was used to guide the reporting of the current study and includes a suggestion for reporting how many articles were identified through sources such as reference lists. While this approach allows for relevant articles to be targeted there is a risk of bias in this approach. Cooper (1998) highlights the potential problems with such a strategy as authors tend to reference other authors' studies from similar journals or subject areas. This bias means that some articles may be more likely to occur in some reference lists and studies that do not belong to these groups are less likely to occur in the articles' references. This approach of searching reference lists for possible articles was therefore used alongside the primary literature search of the three online databases in the current study.

The review highlighted a potential risk of bias in studies that assess carers' experiences as the perspectives sought are often only from the carers themselves. Carers and the person with an ID may differ in their perspectives, as the findings in Viecili et al.'s (2009) paper would suggest. A further risk of bias is that using semistructured interviews, as the majority of studies did, will sometimes inevitably result in participants speaking about subjects that they may not have voluntarily spoken about, had open-ended questions been used. A type of circular argument can result where researchers ask only those questions they are interested in and so the answers can only be related to their questions and areas of interest. Some studies decreased this potential bias by using open-ended questions to allow the participants to raise subjects that interviewers may not have been aware of.

Future Directions for Research

Future reviews could use systematic reviewing methodologies to ensure a clear focus for the review and that appropriate research is identified. Future research could focus on the main outcomes from these studies, including research into diagnoses, decision making and self-determination, how carers and the people they care for differ in their perspectives, and communication between professionals, carers, and people with an ID. A concern for carers that was reported in this review is planning for the future and whether the person with an ID will continue to receive adequate support. Future research could also investigate how best to support carers to feel confident that the person they care for will receive appropriate support as they age.

In relation to study design, future studies should demonstrate that there are sufficient sample sizes to provide a rich account of participants' perspectives. The papers in the review utilised a range of different analysis methods with some papers not describing what specific method they used. The use of structured formalised qualitative analyses is recommended to ensure that themes are robust and to improve study validity. Future studies should also provide a sufficient amount of information in their method sections, to allow for clear replication of their study by other researchers, and for comparisons between different methodologies.

Conclusion

This literature review utilised qualitative systematic reviewing methodologies to set out a search strategy, to search online journal databases, to present a summary of the relevant research into the perspectives of family carers for people with an ID, and to critically discuss the studies included in the review. The search of online databases yielded 12 full articles that were

included in the review. The findings from the studies in the review focused on carers' experiences of symptoms and diagnosis, on stressors and difficulties they experience, their sources of support and coping strategies, their suggestions for improving services, that carers and the person they care for often have different perspectives, and that carers often have concerns about the future. Limitations and directions for future research were discussed.

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How do Carers of People With an Intellectual
Disability With Dementia Experience Their Role and
the Support They Receive Through Services?

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as a thesis for the degree of Doctor of Clinical Psychology

in May 2014

Supervised by Dr Phil Yates

Word Count: 7998

Title of nominated journal: Journal of Intellectual Disability Research

Abstract

Background

People with an intellectual disability often require carers to provide assistance in their basic living needs and to help them achieve the best quality of life possible. The increased prevalence of dementia in people with an intellectual disability over recent years has prioritised the importance of research into the impact this has had on people with an intellectual disability with dementia, their carers, and their support services. There has been a lack of qualitative studies investigating the experiences of carers for people with an intellectual disability and dementia and their perceptions of services that support them to carry out their role. These carers fulfil an important need within the community and this study explored family and paid carers' experiences of caring for people who have an intellectual disability with dementia.

Method

This paper describes a qualitative study that used semistructured interviews to investigate both paid and family carer's experiences of caring for people with an intellectual disability with dementia. Face-to-face interviews were conducted with 12 carers and the resulting data were analysed using thematic analysis.

Results

The analysis generated 9 meta-themes including *a carer's identity, transitions in the carer experience, self-care, difficulties in caring, changes to services, recommendations for change, barriers to accessing carer support, sources of support and resources, and sharing carers' best practice.*

Conclusions

The implications of the results are discussed and recommendations for

future research are provided.

Keywords: Carer, intellectual disability, learning disability, dementia, qualitative, support.

How do Carers of People With an Intellectual Disability With Dementia Experience Their Role and the Support They Receive Through Services?

People with an intellectual disability (ID) experience impairments that often requires them to access social, emotional, and health support. Family and professional paid carers assist people with IDs in areas such as communication, learning, accessing other support and services, socialising, their basic living needs, and to enhance their quality of life (Hubert & Hollins, 2000). People with an ID are particularly vulnerable to developing dementia over their lifetime (Bush & Beail, 2004; Prasher, 1995). While studies have investigated IDs and dementia (Lehmann et al., 2012) there has been a significant lack of qualitative research into investigating carers' views (Mansell & Wilson, 2010), and in particular the experience of carers for people with an ID and dementia.

"Intellectual disability" or "learning disability" is defined in the DSM-IV as a developmental disorder that includes both an intellectual impairment of an IQ under 70, and is associated with social and functional impairments (APA, 2000). People with an ID "have evidence of delayed or abnormal early development together with significant intellectual and functional impairments... [is] lifelong and therefore continuing into later life" (Holland, 2000, p. 26-27). These intellectual and functional disabilities are described in the "Valuing People Now" white paper as significant reductions in ability to understand new information, difficulty learning new skills, difficulties with coping independently, and impairments in intellectual and social functioning (Department of Health, 2001).

Dementia can be defined as "a disorder leading to loss of cognitive functions" (Perry, Hammond, Marston, Gaskell, & Eva, 2011, p. 162) including

a progressive decline in memory, communication, daily living skills and functions, mental ability, and personality or mood changes. In 2013 the prevalence rate of people with dementia in the UK was estimated to be 1.3% of the entire population, with people aged 65 and over having a dementia prevalence of 7.1% among that population (Alzheimer's Society, 2014). However, about 12% of people with an ID develop dementia by 65 years of age, and over half of people with Down's syndrome develop dementia by the time they are 70 (Prasher, 1995). Recent changes to the quality and access of care for people with an ID has resulted in a significant increase in their life expectancy (Holland, 2000; Hubert & Hollins, 2000).

Service guidelines on the management of dementia recommend support and treatment for carers (NICE, 2006). The National Audit Office reported that services for people with dementia were not delivering consistently and that there were deficiencies in carer support (NAO, 2007). Focus groups with carers and people with dementia show that diagnoses of dementia are "often poorly communicated" (NAO, p. 8) and sometimes not set out in writing. Studies have also outlined the possible negative health effects and emotional difficulties associated with the carer role (Möller-Leimkühler & Wiesheu, 2012). Types of coping strategies used by carers have been found to be related to depression (Saad et al., 1995) and physical health issues (Baumgarten et al., 1992).

A theoretical model specific to carers' experiences that provides a framework for understanding burden and stress is Pearlin, Mullan, Semple, and Skaff's (1990) stress-process model of stress in carers. Pearlin et al.'s model was based on a qualitative study that interviewed 555 carers for people with dementia over a 2 year period. The model outlines how a carer's background (including culture and personal history), their own psychological strains (such

as the carer's self-esteem), stressors relating to the person being cared for (such as their cognitive status or problematic behaviours), stressors related to external elements of the carer's life (e.g. other family issues, job conflicts, economic issues), sources of support, and their own coping strategies all play a significant role in carers' ability to cope with the role (Pearlin et al., 1990).

Qualitative studies investigating perspectives of family carers for people with an ID have provided support for Pearlin et al.'s model. Studies reported that carer stressors included difficulties with practical duties of the role (Kenny & McGilloway, 2007), insufficient knowledge or skills (Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004), concerns about accessing respite care (Mansell & Wilson, 2010; Wodehouse & McGill, 2009), and worrying about the future care of the person with an ID (Kenny & McGilloway, 2007; Mansell & Wilson, 2010; Weeks, Nilsson, Bryanton, & Kozma, 2008).

In Pearlin et al.'s (1990) model sources of support are a key contributing factor in carers' ability to cope. Subsequent research into carers for people with an ID found that helpful sources and types of support included problem focused coping strategies, being realistic about the person's disorder, and accessing information about the disability (Kenny & McGilloway, 2007). Carers for people with an ID have also reported difficulty with accessing information from services (Mansell & Wilson, 2010; Wodehouse & McGill, 2009), that services were unsupportive and not understanding (Power, 2008; Weeks et al., 2008), that carers worried about future service funding (Weeks et al., 2008), and that carers felt that good communication and relationships between GPs, carers, and people with IDs was important (Ziviani et al., 2004).

Qualitative studies with carers for people with dementia without an ID have shown that the diagnosis of dementia confirmed what carers expected

(Derksen, Vernooij-Dassen, Gillissen, Olde Rikkert, & Scheltens, 2006), that carers reported difficulty with planning for the persons future care (Livingston et al., 2010), and while some carers felt their interaction with GPs and care staff was good (Downs et al., 2006), carers in other studies reported generally negative interactions with support services (Jurgens, Clissett, Gladman, & Harwood, 2012).

The experiences of family carers for people with an ID and dementia is an under researched area of study. A literature search of three online journal databases (PsycINFO, Science Direct, and Web of Science) retrieved only one article that met the inclusion criteria for a qualitative study of family carers for people with an ID and dementia (Bromley, 2014). Deb, Hare, and Prior (2007) conducted a qualitative study on family carers' perspectives of symptoms of dementia among people with Down's syndrome. This study reported "many similarities in the clinical presentation of dementia in adults with Down's syndrome and the non-intellectually disabled population" (p. 726), such as forgetfulness and confusion. Further studies into carers for people with an ID and dementia are required to better understand how carers experience their role and their use of services.

Research Questions and Study Aims

Research Questions

1. What are carers' experiences of their role of caring for people who have an ID and dementia?
2. What are carers' experiences of the support they receive through carer services?

Study Aims

1. To investigate what carers feel helps or hinders their ability to act as

carer.

2. To determine whether participants feel they have experienced any mental health or health problems since they became a carer.
3. To explore what carers do for self-care.
4. To find out whether carers have access to support groups and the possible barriers to accessing support.
5. To explore carers' experiences of receiving the diagnosis of dementia.
6. To explore any differences or similarities between paid and family carers experiences.

Method

Design

The study used semistructured individual interviews to investigate carers' perspectives. A qualitative methodology was used as this has been found to capture complex factors in human experience (Kazdin, 2003), and is appropriate for subject areas that have had "little previous research, [and] where there is an interest not only in the outcomes but also in the process of human interaction" (Ziviani et al., 2004, p. 214). The current paper utilised the COREQ, or consolidated criteria for reporting qualitative research. The COREQ is a 32 item checklist that can be used to improve "transparency in research methods... [and] the quality of reporting of qualitative studies" (Tong, Sainsbury, & Criag, 2007, p. 356). The COREQ criteria were used to report the study design, analyses, and findings in the current paper.

Participants

The inclusion criteria for participants were carers for people with an ID and dementia living in Devon. The exclusion criteria were carers aged below 18 years old. The interviewer is male and was a trainee clinical psychologist with a

completed PhD in psychology. The study used purposive sampling and participants were identified through contacting NHS clinical psychologists working with people with IDs and dementia. Only potential participants who were considered suitable by the psychologists in that location were contacted. The two reasons why potential participants were not contacted by the researcher were that one carer had moved away from Devon, while another carer's person they cared for had recently died and the clinical psychologist and researcher decided it would not be appropriate to interview them as they were still too emotionally upset. The researcher attempted to contact 13 carers but one carer could not be contacted despite the researcher's attempts. Twelve carers were interviewed face-to-face at their home or at their place of work.

Guest, Bunce and Johnson (2006) suggest that 12 interviews are required to reach data saturation for a relatively homogenous sample. Data saturation can be defined as the point when the analysis of additional new data "no longer brought additional insights to the research question[s]" (Jorgenson, Muller, & Whelan, 2012, p. 2). Data saturation is considered a "gold standard" (Guest et al, 2006, p. 60) for determining appropriate sample sizes for qualitative studies. Following Guest et al.'s (2006) suggestion of 12 interviews made it likely that a suitable amount of interviews were available for a thorough analysis of the data.

Data collection included gathering information on participants' demographic characteristics at the start of each interview. The sample was comprised of five family carers and seven paid carers. The sample's average age was relatively elderly ($M = 64.25$ years, $SD = 17.29$) with the paid carers having an average age of 51.85 years old ($SD = 11.05$) and family carers an average of 81.60 years old ($SD = 5.75$). The age range for all carers was between 36 years and 92 years old. Three of the family carers were parents of

the person who had an ID and dementia and two family carers were the person's sibling. Of the family carers two of the people with an ID and dementia were deceased. The carers were predominantly female (Female $N=11$, Male $N=1$), all of the people being cared for male, and all of the sample was living in the South West of England, English speaking, and White.

Interview

The interviews were conducted in person with carers using a semistructured interview (see the interview schedule in Appendix C). This methodology was used in order to flexibly ask both specific questions related to the study's research questions and open-ended follow up questions to allow participants to express their views. The interview schedule was developed through the researcher being familiar with recent literature in the field and through discussions with clinical psychologists working with people with IDs and dementia. The interview schedule was then considered and critiqued by the researcher, clinical psychologists, a qualitative analyst, an examination panel of research and clinical psychologists, and three different ethics boards before the interviews were conducted. The researcher then conducted two interviews with participants before making slight amendments to some of the questions in the interview schedule. This allowed some questions to be more open-ended to best capture the areas of interest and any emerging themes, as well as to investigate participants' experiences that the researcher may not have envisaged in the original interview schedule. The remaining interviews were then conducted following NHS Trust and NHS ethical approval of the minor amendments to the interview schedule.

Procedure

Issues of confidentiality, informed consent, participant withdrawal,

research termination, data protection, risk, debriefing, personally sensitive topics, and use of findings are outlined in the participant information sheet (Appendix A) and consent form (Appendix B). Following NHS Trust and NRES ethical approval (see Appendices D and E) the researcher contacted clinical psychologists working in ID services. The psychologists contacted carers to assess appropriateness of them taking part. Potential participants were then sent letters with the study information sheet and contacted by the researcher.

Two pilot interviews have been used in previous qualitative research to assess the interview schedule (Wodehouse & McGill, 2009). Two pilot interviews were undertaken in the current study and the remaining interviews were then conducted, recorded, and transcribed. During the interviews any emotional distress of participants was managed by the interviewer who had experience of conducting semistructured interviews with people with mental health difficulties. A recommended transcribing company transcribed the majority of interviews while the interviewer transcribed a third of interviews to become familiar with the data. All interviews were analysed using thematic analysis and themes were housed in a qualitative research program, QSR International NVivo 10 software. An inter-rater reliability check was then carried out on a sample of data with two trainee clinical psychologists with experience in thematic analysis. While many codes and themes matched those generated by the researcher there were slight differences between some themes. These differences were taken into account in the final analysis and themes.

Approach to Data Analysis

The interviews were analysed using thematic analysis. Braun and Clarke (2006) define thematic analysis as a flexible analytic method that is used for “identifying, analysing and reporting patterns within data” (Braun & Clarke,

2006, p. 79). Thematic analysis is appropriate for analysing the complexities of carers' experiences and is a useful analytic method for "capturing the complexities of meaning within a textual data set" (Guest, MacQueen, & Namey, 2011, p. 11). The analysis of codes and themes that were identified in the data were done in an "inductive or 'bottom up' way" (Braun & Clarke, 2006, p. 83). Two approaches to generating themes are an inductive approach, that is data-driven, and a deductive approach using "the investigator's prior theoretical understanding of the phenomenon under study" (Ryan & Bernard, 2003, p. 88). While the current study used an inductive approach to identify codes and themes the analysis also included elements of a deductive approach that included the creating of an interview schedule informed by research on the subject of carers, and coding of data by a researcher with some understanding of relevant research. McQueen et al.'s (2009) study describes a similar acknowledgment that the current study makes in recognising that an element of the design and analytic approach is deductive, but that themes also emerged from the data in an inductive way:

Thematic analysis is a process for encoding qualitative data that supports our use of a mixed inductive and deductive approach to coding and analysis. Using our research questions to narrow the scope of analysis, themes emerged from the coded data and also were informed by the literature and the expertise of the research team. (p. 1229)

This flexibility could be considered a strength in the current study's design as, "exclusively inductive analyses may neglect important insights from the theoretical or empirical literature" (Gardner, Davidson, McAteer, Mitchie, & Evidence into Recommendations Study Group, 2009). The current study therefore recognises that although it uses an inductive approach there is an

element of deductive reasoning at some points in the analysis. By asking specific and open-ended questions in the interview and by allowing themes to emerge from the data in the analysis, rather than searching for only specific themes, the analysis was able to capture a variety of meta-themes. Some of these themes were more related to research questions while other themes emerged more organically from carers' perspectives. Johnstone (2004) discusses this analytical position and explains how there is "support for mixing in a single study ways of thinking about data, indeed, that both inductive and deductive reasoning can be complementary, rather than mutually exclusive, data analysis tools" (p. 262).

The data analysis followed Braun & Clarke's (2006) six phases of thematic analysis which includes: "Familiarizing yourself with your data" (transcribing, rereading, making notes), "generating initial codes" (writing down central aspects), "searching for themes" through collating codes, "reviewing themes" (assessing whether themes relate to the codes and data set), "defining and naming themes", and finally "producing the report" (presentation of theme names, selection of extract examples, writing the report; p. 87). The codes and themes emerged from the data as opposed to being identified in advance of the analysis. One researcher coded the data by identifying central aspects in participants' accounts. The themes were derived from rereading and collating codes. The themes were identified at the semantic level where the "themes are identified within the explicit or surface meanings of the data" (Braun & Clarke, 2006, p. 84). The themes were then reviewed and meta-themes were developed based on collating related themes. While saturation in an inductive approach means that further interviews could produce new themes, the analysis of paid and family carer interviews was found to add relatively few new

emerging themes, and so data saturation was judged to have occurred.

Validity and reliability in quantitative and qualitative research is enhanced through minimising bias (Golafshani, 2003). In the current study's thematic analysis the investigator bias was minimised through closely following Braun and Clarke's (2006) suggested analytic steps, and through the researcher ensuring that the generated themes were supported by carers' statements. The themes' reliability and validity were also demonstrated through the inter-rater coding of excerpts from a sample of transcripts and "a rigorous and systematic data collection process" (Patton, 2002, p. 266). This rigor in data collection and inter-rater reliability are considered to be established approaches for enhancing validity and reliability in qualitative studies (Patton, 2002).

Results

Following a reading of the transcripts, the coding process, and the initial development of themes it was apparent that there were more shared experiences between paid and family carers than differences between them. This resulted in some meta-themes that incorporated information from both paid and family carers, while information that was provided by only one group of carers and not the other was presented as independent meta-themes. Altogether nine meta-themes were generated including six meta-themes that were shared by both paid and family carers. The remaining three meta-themes included two that were specific to paid carers, which related to them working within staff teams and having access to information on best practice, and one meta-theme specific to family carers, on barriers to accessing carer support. In these results the shared meta and sub-themes are presented in Table 2.1 and the themes that are specific to each group of carers are presented in Table 2.2.

Table 2.1

Summary of Family and Paid Carers' Shared Meta and Sub-Themes

Meta-Themes	Sub-Themes
Family and paid carers' shared themes	
A carer's identity	e.g. A sense of purpose, being a carer is more than "just a job"
Transitions in the carer experience	Becoming a carer Life before dementia Diagnosis of dementia Life with dementia End of life
Self-care	Strategies for keeping well Helpful carer traits Accessing respite care
Difficulties in caring	e.g. Physical or mental health difficulties, making time for self
Changes to services	Perceived changes to services Positive consequences to changes in services Negative consequences to changes in services
Recommendations for change	Delivering diagnosis Communication between services, clients, and families Carer support groups Access to information and resources Training Respite Care

Table 2.2

Summary of Family and Paid Carers' Separate Meta and Sub-Themes

Meta-Themes	Sub-Themes
Family carers' themes	
Barriers to accessing carer support	Not being aware of support services Independent generation Negative previous experience Support not available in past so low expectations for access to support
Paid carers' themes	
Sources of support and resources	Staff team support Outside agency support Carer support groups Training Information resources
Sharing carers' best practice	Approach to working with person Fostering togetherness as a staff team Appropriate environment and equipment Including families Sharing information of best practice Accessing support for self when needed End of life

Family and Paid Carers' Shared Themes

A carer's identity. Both paid and family carers tended to take some pleasure in being a carer, "*I quite enjoyed the role as being a carer*", and felt that it was a special and unique role that they took pride in. Many family carers associated themselves so much with "*the carer*" role that this often made it difficult for them to access support. The role gave many a sense of purpose and paid carers described the work as more than "*just a job.*"

I do think it's not just a job, it's more... oh, 'calling' sounds a bit corny, doesn't it? But it's something... Not everyone can do it, and it's something you have got inside you that makes it a little bit special. (paid carer)

Carers tended to report feeling fortunate in their role compared to other peoples' situations. This comparison appeared to allow carers to remain positive, "*I think it would be harder for someone else whose husband and wife is, what I would call, normal and then they get Alzheimer's. I think they would find it more difficult than what I did.*" Many paid carers felt that they chose to be carers rather than feeling obliged through the person being a family member, "*It's my choice to be a carer. I don't have to do this role or job so it's very different for somebody whose got a family member who you suddenly have to care for. I've chosen this profession.*" This process of both paid and family carers comparing themselves to other types of carers may allow them to take up more powerful positions rather than feeling they had little choice in their carer duty.

Transitions in the carer experience. The analysis identified several distinct transitional phases in both family and paid carers' experiences over their lifetimes. This meta-theme contained the highest amount of sub-themes in the analysis.

Becoming a carer. People became carers via many routes. Some paid carers became a carer to provide something for their community, “*I wanted to give something back... and from day one, I’ve loved it*”, while others first cared for family members and then became professional carers. Parent carers tended to express a duty for “*bringing them into the world*” and sibling carers became carers when their parents passed away.

Life before dementia. Carers reported that the people they care for were active before developing dementia and engaged in work (bakeries, pubs, and workshops) and hobbies (music, sport, ballroom dancing, puzzles, and socialising).

Diagnosis of dementia. The diagnosis of dementia often began with paid and family carers noticing changes in the person cared for. Carers reported that the diagnosis of ID many years ago was often insensitively communicated, if at all, while more recent diagnoses were often communicated with minimal information. Many carers felt that knowing the likelihood of people with IDs developing dementia prepared them for recognising dementia related symptoms, “*That’s another thing that she explained... Because they are living longer now... they are finding they are going into dementia.*” In addition, a paid carer explained that the presence of the ID made it difficult to identify dementia.

Because with a learning disability it’s hard to tell... his memory is impaired because of the learning difficulties... he could have had it for years before I even picked anything up... So the learning disability makes it really hard to actually diagnose [dementia]. (paid carer)

Life with dementia. People with an ID and dementia experience changes in their ability to function and maintain relationships. Paid and family carers observed the person they cared for becoming forgetful, speaking

inappropriately, not being able to do activities independently, becoming disoriented, and striking out at the carer. Carers also observed a decline in the person's ability to recognise the appearance and names of the carers and other workers, *"I was called everything else under the sun. He'd recognise my face, but just change my name."* These changes due to dementia had negative consequences for the nature of the relationship as well as possibly increasing the risk to the carer.

End of life. Important decisions are required when a person with an ID and dementia comes to the end of life. While family carers acknowledged the need for the person to move from their care into an appropriate service not all family carers were comfortable with this transition, *"I was really upset because I couldn't have him home [when he passed away]."* Family carers also experienced difficulties after the person had passed away due to the relationship playing such a significant role in both their lives, *"I feel lonely sometimes... because [Brother] and I used to do a lot together... I was so used to him sitting there... I just miss [Brother], really."* Many family carers worried what would happen to the person they care for when they themselves passed away, *"It's me. It's my age. If anything happens to me, he's got to go with other people. And he's never been away from me."*

Self-care. Carers reported a range of different ways they engaged in self-care.

Strategies for keeping well. Paid and family carers engaged in strategies for keeping well and relaxing including walking, running, socialising, attending church, surfing, computer games, palates, exploring, and travel.

Helpful carer traits. Carers described traits or approaches that helped them to carry out their role, such as not taking issues from work home with

them, acceptance, *“we accepted the situation”*, resilience, *“we take it in our stride”*, encouraging the person to engage in activities that others do, *“he’s never been left out of anything”*, a sense of humour, *“I have got a bit of a daft sense of humour... if you can’t laugh, it’s not worth going on”*, patience and empathy, *“it’s just patience, empathy as well like I can try to put myself into their position and think about what they’re going through and if it was me how would I like things to be done.”* In addition, paid carers tended to use phrases for their caring role, such as caring for clients in the same way they would care for a member of their own family, *“It should be as what you would want... so the quality of what you would want or for your relatives to come into. It should be those same high standards of care.”*

Accessing respite care. Respite care used by family carers included the person being cared for staying for a night away or for respite workers to come into the carer’s home for a few hours. Many family carers had positive experiences of using respite care, *“it was beautiful and they were so good. They used to love having [Brother] out there... That did help a lot, you know. I could get things done that I couldn’t really get done when [Brother] was here.”*

Difficulties in caring. Some family and paid carers explained that due to their caring role they had experienced physical health problems, such as injuring their arm or back in moving and handling the person, and had experienced mental health problems such as stress related anxiety and depression. One carer felt that it is common knowledge that carers and nurses inevitably sustain injuries and stress from their work.

I had a back injury... I was off quite a while with that. And I’m a nurse, aren’t I, so I’ve been off with stress...maybe because you are caring for other people all the time and you just don’t look after yourself as much... I

don't know hardly anybody [carers and nurses] that I have worked with in a lot of years that hasn't... been off with stress or on medication. (paid carer)

However, the majority of participants reported not experiencing physical or mental health difficulties due to caring. Difficulties that carers described included making time for themselves and feeling unable to leave the person alone.

Changes to services.

Perceived changes to services. Many carers discussed significant changes in recent years to services including a transition from more central ID services to those based more locally in the community.

Positive consequences to changes in services. Family carers generally described service staff, such as nurse staff, psychologists, and social workers, as very good, *"The people on the ground floor you can't say a word against them. I mean they're good."* Family and paid carers discussed their involvement in memory clinics, care homes, and respite care. Some paid carers outlined the positive consequences of the change to more person-centred care in smaller community-based services.

*When the institutions closed, the place that he was in was like a smaller type of institution... they didn't have anything in place for the growing/aging population, people with Down's syndrome. So, unfortunately...he was quite neglected, really, because they didn't know how to cope with him. So he came here [community based nursing home] and improved quite a lot.
(paid carer)*

Negative consequences to changes in services. Participants raised several negative consequences of service changes including difficulties with attempting to engage people in employment when they are not actually able to

work, that reductions in funding to services has reduced the variety and amount of activities for clients and their workers, that cuts to funding has led to workers who have left not being replaced, “*There’s lots of cutbacks... when [Self-employed carer] left, they never replaced her*”, and that closing and splitting up central services results in rupturing established supportive relationships between workers, clients, and carers. In addition, carers felt that some carers’ groups had closed down since the recent service changes.

This Care in the Community, um, it’s changed the whole thing from when it first started... I think it’s in a bad way personally for somebody like [Son] whereas when he started he went to this particular centre which was purposely, purpose built. It had its own workshop where they could do packaging. It had its own kitchen, so food. The staff organised things on like a Friday there’d be a disco. A lot of people from the area used to come there but as soon as they started chopping and changing it got all split up so he lost a lot of his friends, is what I’m trying to say and I think to me that that was bad... if I go back to what I call the old system before the first lot of cuts came in we used to have regular carers meetings for people with learning difficulties. Carers for people with learning difficulties. So you’re all talking about the same thing. Those services now seem to have gone.

(family carer)

Recommendations for change. The following themes represented carers’ key recommendations for improving their ability to carry out their role.

Delivering diagnosis. Both paid and family carers felt that appropriate information should be sensitively communicated at the time of the diagnosis.

Communication between services, clients, and families. Many participants emphasised the importance of good communication between

services and themselves. Carers who had established relationships with workers in ID services often felt better informed of the increased risk of the person they cared for developing dementia, *“the psychologist [had] mentioned it. It was no shock.”* Family and paid carers talked about how helpful it was for the person with an ID and dementia to have regular contact with those familiar to them, *“But my sons, when they visit from London, and my grandchildren, he loves to see them... they speak to him every week on the phone to try and keep them in his memory.”*

Carer support groups. Family carers reported that carer groups were helpful and paid carers felt that carers groups would help them to reflect on and gain support from other carers. One paid carer suggested that paid and family carers would benefit from a support forum.

Access to information and resources. Many family carers wanted more information about dementia and available services while almost all paid carers stressed the importance of resources and information.

Training. Paid carers felt that more training specific to dementia would be of benefit to themselves and other staff members.

Respite care. Family carers expressed the importance of continuity in respite care, *“you need one really because they... got used to the one person coming to see to him... It’s familiarity... They just need to have a regular person each time.”*

Family Carers’ Themes

A main difference between family and paid carers were the many difficulties family carers experienced with accessing carer support.

Barriers to accessing carer support. Family carers reported several reasons for why they found it difficult to access carer support services.

Not being aware of support services. Many family carers felt they were not aware of services for themselves or the person they cared for, “*Well its really knowing what’s out there. Its surprising, nobody tells you anything.*”

Independent generation. Many family carers reported not using services because they considered themselves to be independent. One paid carer felt that many family carers did not access support for themselves because they were part of a generation that felt it would be shameful to ask for help with their family member. All the family carers were older adults and there appeared to be a shared sense of belonging to a generation that were proud to be independent.

I mean at the moment now with the dementia we’ve put in for a respite you know, but other than that I haven’t bothered with respite or anything else like that [in the past]... Well I haven’t wanted to [laughter]. Haven’t bothered... because we’ve managed on our own. I’m independent, put it that way. Yeah, yeah. You know I don’t just ring up this and ring up that. I’m not one of those that keep on pestering people like that. No. So we thought “Well now is the time perhaps for respite because we’re getting older and eventually perhaps he’s got to go in somewhere”... we’ve just done it ourselves and that’s it. (family carer)

Negative previous experience. Some family carers had negative experiences of using respite care and although this happened many years ago, it caused them to be wary of utilising these services again in the future.

Support not available in past so low expectations for access to support. Some carers who talked about the lack of support in the past appeared to have very little expectation that services had grown and could now provide greater support.

Paid Carers' Themes

Paid carers had two meta-themes that were distinctly separate from the experiences of family carers. Paid carers spoke of an abundance of information, staff support, and resources available to them. Paid carers also described best practices in caring.

Sources of support and resources. Paid carers used many sources of support that they felt were fundamental in carrying out their role.

Staff team support. Many paid carers talked about how they were able to access staff team support and the benefits this had on their ability to cope with difficulties.

[I experienced] Stress and depression... it sort of creeps up on you without you fully acknowledging that it's happening. Yeah, then it just sort of hits you... I had support from my staff when I returned, but also from senior management. (paid carer)

Outside agency support. Many paid carers emphasised the importance of their interactions with other professionals in making appropriate referrals, accessing others' expertise, acknowledging one's own limitations, and maintaining an awareness of the carer role and the delivery of carer services.

We are not afraid to put referrals in. Because some people view it as oh you are not coping, but it's about accessing different people's expertise... it's about that loop, I suppose, where it links everybody together. (paid carer)

Carer support groups. Some paid carers were aware of carer support groups but most carers had not felt the need to utilise them.

Training. Paid carers described training available to them including dementia awareness training, moving and handling, and best practice for

working with people with ID related training.

Information resources. Paid carers had access to a range of information and some carers were very pro active in finding and sharing this information.

Sharing carers' best practice. This meta-theme includes several suggestions for best practice that paid carers wanted to share in the interviews.

Approach to working with person. Paid carers described their general approach to working with people with an ID and dementia that included reassuring the person, to always keep them safe, to acknowledge the importance of each interaction, to work holistically, and to be person centred.

Fostering togetherness as a staff team. Many paid carers talked about the importance of the staff team and working in a supportive environment.

Appropriate environment and equipment. Paid carers emphasised the importance of the working environment and that appropriate equipment can reduce work related injuries.

Including families. Many paid carers reported the importance of including the family and keeping them informed of the person's care.

Sharing information of best practice. Paid carers tended to report that sharing of information between professionals and families was a key element of their role.

Accessing support for self when needed. Most paid carers felt they were able to access counselling or support for themselves if they need to.

End of life. Managing the end of life for people with an ID and dementia required an understanding of best practice for the client as well as providing support to staff following the person passing away, "*went for a couple of [counselling] sessions... most of the staff felt that talking about it [a client with an ID and dementia passing away] within the team helps.*"

Discussion

The Analysis and Previous Literature

Through the analysis nine meta-themes were generated including six meta-themes shared by both paid and family carers, two meta-themes for only paid carers, and one meta-theme for only family carers. The current study identified similar symptoms in the person with an ID and dementia as those reported by Deb et al.'s (2007) study. Deb et al. reported that people with Down's syndrome and dementia display similar symptoms to those people with dementia in the normal population. These symptoms were similar to those in the "life after dementia" theme in the current study. In addition, one of the paid carers in the current study reported difficulty with assessing change in the person with an ID as some ID symptoms, like memory problems, may overlap with dementia symptoms. The findings from Deb et al.'s study and the current study suggest that carers are witnessing these changes in behaviour and that it could be beneficial to be informed at an early stage of what changes to expect.

The current study's findings both replicate and differ from previous qualitative studies that investigated the experiences of carers for people with only an ID and not dementia. Many themes from the study provide further support for Pearlin et al.'s (1990) stress process model. As in Pearlin et al.'s model, themes from the current study stressed the importance of sources of support for carers in the themes of "carer support groups", "accessing respite care", "communication between services, clients, and families", "training", and "staff team support." Replicating Kenny & McGilloway's (2007) findings the current study's carers reported that accessing information about caring and the persons' disability helped them to cope with their role. Power's (2008) qualitative study found that family carers reported services to be non

supportive, which was represented in the current study's themes of "barriers to accessing support" and "negative consequences to changes in services." The themes of "accessing respite care" and "sources of support and resources", which described support that is available to carers, differed from Power's (2008) findings.

Previous research has found that carers tend to worry about future support for the person they care for (Kenny & McGilloway, 2007; Mansell & Wilson, 2010; Weeks et al., 2008) and these concerns were largely replicated in the current study's theme of "end of life" in the meta-theme "transitions in the carer experience." Many carers felt apprehensive about the future when either they pass away or the person with an ID passes away. These concerns feature strongly in carers' perspectives and could be integrated into Pearlin et al.'s (1990) model, as well as providing a possible area for further research.

Implications of Findings

The experience of change was a pattern that emerged in most meta-themes and included changes in: the experiences of people with an ID once they develop dementia; the increased amount of people with an ID developing dementia; the transitions carers' experience through significant life stages; the nature of the relationship changing after the person develops dementia; and the recent changes to support services. These changes experienced by carers could now be the focus of further research. In addition, there is an implication from the findings that government policy and service provision could benefit from considering a long term approach and re-assessing the very concept that change is always for the better. When taking into account the breadth of change carers and clients are already experiencing, further large scale change may not always be to the benefit of those using these services.

Paid and family carers were generally happy in their role and the majority reported that theirs was a positive experience, "*I wouldn't have changed it for the world.*" Family carers' use of services tended to reflect three distinct experiences. The first experience was those carers who did not historically use services for themselves and only recently accessed them as they were getting older. A second type of carer experience was those who had used carer support services for a long time and largely found staff to be professional and supportive, a finding that supports Downs et al.'s (2006) study. However, both of these types of family carers tended to discuss the lack of diagnosis information they received, which replicated past findings regarding poor communication in the diagnoses of dementia (NAO, 2007). The meta-theme of "barriers to accessing support" highlighted some of the main reasons why carers were not accessing carer support, or felt uncomfortable doing so, and these included not being aware of support and having been in an "independent generation." The implications of these findings for clinical psychologists and other support staff are to recognise that more information could be provided to carers to prepare them for recognising the symptoms of dementia. Information for carers could also include user accessible details of support services for carers themselves, as well as offering carer focused training on moving and handling, self-care strategies, etc. However, the study's findings suggest that what is also needed is an attempt to actively destigmatize the negative connotations some carers have with asking for help. Services could educate staff that carers may resist support based on perceived negative stigmas and difficulties with asking for support for themselves. It may therefore be necessary to offer family carers support on an ongoing basis to provide them with ample opportunities of challenging stigmas and accessing help as they age and their

circumstances change.

The third experience of family carers was carers who had used services like respite care for a long time and now felt that services had deteriorated in recent years. A main negative consequence reported by participants was that each time the services “*chops and changes*”, where established centres and services are split up into smaller community-based services, it is not only the service that is split up but also many of the relationships between clients, carers, families, and staff in those services. These possible impacts on relationships and the quality of life for clients and carers could be taken into consideration when making future large scale changes to services.

Previous qualitative studies have highlighted the important role of partners, family, and friends in family carers' ability to cope where, “many appear to have benefited from the ‘buffering’ effect of the support provided by their spouses/ partners and families” (Kenny & McGilloway, 2007, p. 226). In addition, Kenny and McGilloway found that three-quarters of parent carer's received support from other parent carers and these relationships may have been a significant mechanism in their ability to cope. The current study replicated these findings in the themes of “carer support groups” and “negative consequences to changes in services” where family carers talked about relationships they fostered with other carers and how these relationships could be an important source of support.

The study's findings have theoretical implications for Pearlin et al.'s (1990) stress-process model of stress in carers. The model has several strengths for use in researching this area including that it is clinically relevant, that it appears in much of the carer related literature, and that it is a comprehensive model that includes a number of factors in carers' experiences. Many of the current study's

meta-themes reflect the influential mechanisms and stressors of Pearlin et al.'s model and provide evidence for the validity of the model. The themes showed that factors such as the presence of family or neighbours, previous history of being a carer, possessing helpful carer traits like patience and acceptance, and having positive self-care strategies, all have a significant influence in a carer's stress and ability to cope with that stress. The study provided further evidence that carers report a range of stressors including physical and mental health difficulties (in the "difficulties in caring" meta-theme) and in difficulties with accessing services (the "barriers to accessing carer support" meta-theme). This study also included several factors in carers' experiences such as "barriers to accessing carer support", "transitions in the carer experience", "sources of support and resources", and "sharing carers' best practice." These could be integrated with Pearlin et al.'s model to further capture carers' experiences, influencing mechanisms, and factors in their ability to cope.

Limitations

Recruitment excluded carers considered too vulnerable or emotionally upset to participate. While this decision was made on ethical grounds the consequence is that these carers may be part of a group that should be a priority for services and interviewing them may have resulted in quite different themes. Only those carers who were known to NHS services were contacted. The results are therefore limited to describing those carers' experiences that are in contact with services. The study interviewed 12 carers which is a relatively small sample of people. The sample also included only one male carer, no younger carers, and all of those people cared for were male. Therefore, any generalisability from the study about carers' experiences needs to be made cautiously.

After the first two interviews the interview schedule was tested for sensitivity to themes and only required a minor amendment. However, the possibility that this process could have shaped alternate responses, however slightly, must be acknowledged. A further limitation is that data saturation was reached at 12 interviews but it is impossible to assess whether new interviews would produce further new themes without conducting and analysing further interviews. Viecili, Lunskey, and Strike (2009) found that carers and the person with an ID agreed with each other about what was important only around half the time. The current study only interviewed carers so it must be acknowledged that their perspectives would not necessarily also represent the perspectives of the people they care for.

Both family and paid carers tended to project the image of someone able to cope. Family carers reported that what they were doing was simply what anyone would be expected to do. This position of perceiving the carer role as a duty that one should not complain about and should always appear to be coping with, may have influenced carers reporting that they had not experienced physical or mental health difficulties. This image of being a perfect carer may have affected how other interview questions were answered as well as being a possible reason for why some carers did not seek carer support.

Future Research

As reported in the meta-theme “barriers to accessing carer support” many carers were not using or aware of services for carers. Future studies could interview carers not in contact with services to investigate their experiences and why they do not access support. Findings from the current study show that services assume people will access them while many carers do not seek out information or support. How to resolve carers’ lack of engagement and to

encourage them to make use of services could be an area for further study.

A possible solution to carer stigma about asking for support could be the provision of education and training in self-care and safe moving and handling. Future quantitative studies could investigate mechanisms in carers who are able to cope with the role and to assess why some carers develop physical or mental health difficulties. This information could help services identify which carers may be particularly vulnerable. Carers tended to compare themselves as lucky and favourable to other types of carer. This approach appeared to allow carers to occupy a more powerful position than those carers who they may perceive as having little choice in their role. Future studies could explore this downward comparison and whether it allows carers to feel better able to cope. Recent years have seen significant changes in ID services and studies could now explore the consequences of these changes.

Conclusion

This area of research is becoming increasingly important due to the likelihood of people with an ID developing dementia and the impact this has on this population, carers, and services. This study set out to gain an understanding of carers' perspectives of their role and their use of services. There has been a lack of qualitative studies in this specific area and this study makes a unique contribution to this literature.

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Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. (2004). Meeting in the middle: Improving communication in primary health care consultations with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 29, 211-225.

Appendix A: Participant Information Sheet



Research Participant Information Sheet

Study Title: How do carers for people with a learning disability with dementia experience their role and the support they receive through services?

Chief Investigator: Andrew Bromley

My name is Andrew and I am a trainee Clinical Psychologist student at the University of Exeter. I am working with Dr Phil Yates on a study where we are interviewing family carers and paid carers who care for people with a learning disability with dementia. We are interested in finding out about how carers see their role as carer, what they feel helps or hinders their ability to act as carer, and what their experiences are of carer support services. In order to explore these important questions relating to carers experiences we would like to invite you to take part in this research. Please read this information sheet carefully before deciding whether or not to take part. If you have any questions after reading this, please contact me directly via my email ... or phone me on ...

Purpose of the study

This study will investigate people's experiences of caring for people who have a learning disability with dementia. This study aims to investigate how carers experience their carer role. The study will also attempt to contribute to a better understanding of support and care, and will provide feedback on what people's experiences are of the support they use, and what support they may feel would be of benefit to them. It will also aim to contribute to knowledge and practice in an area that may represent a significant need in the community: to understand how best to support those who provide fundamental help to people who have a learning disability with dementia.

Summary of the Study

Due to impairments that people with a learning disability have many of these people require assistance from carers. People with a learning disability are in a group that is especially vulnerable to developing dementia. There is a limited amount of research that has been conducted into investigating the experience of carers for people with a learning disability and dementia. In addition, studies into the quality of carer support in the UK has shown mixed results. The proposed study will use a semistructured individual interview to investigate the experience of carers in Devon who care for people with a learning disability and dementia by asking them about their role and the support they have received as carers. The interview will be conducted either over the phone or in person.

Why have I been chosen?

People in Devon who act as carer for people who have a learning disability and dementia are eligible to take part in the research.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive through any services in Devon.

What will happen to me if I take part? What do I have to do?

Taking part in this study involves participating in a single interview either conducted over the phone or in person depending on your preference. You will be contacted by a Clinical Psychologist that works in your area who will ask you if you would like to be sent information about the study. If you agreed to receive this information this participant information sheet was sent to you and you received a phone call from the researcher who arranged a time suitable for you to answer questions about your work as a carer. The interview should take between 30 minutes and an hour to complete, although in some cases may take longer than an hour.

What are the possible disadvantages and risks of taking part?

Being part of this research will involve you giving of your time to complete the interview. Some of the questions in the interview are of a personal nature and sometimes people can find it upsetting to reflect on them as well as talking about the person that you act as carer for. However, you do not have to answer anything you don't want to.

What are the possible benefits of taking part?

The information we get from this study may help us to understand the carers' experiences in their role better and highlight possible ways that current services could support carers in ways that carers themselves have identified. The study may also allow you to reflect on your own experiences as well as allowing you to receive feedback on the results of the research.

What happens when the research study stops?

Should you request it you will be sent information about the results of the research when they are available.

What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanism is available to you (Patient Advice & Liaison Service FREEPHONE 0800 073 0741 or 01392 403621). If you wish to complain about any aspect of the researcher's work you should contact Dr Phil Yates (contact details below).

Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will normally be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognized from it. The main exception would be if a significant risk of harm to yourself or others is identified, in which case information may be fed back to your doctor but normally only after discussion with you.

What will happen to the results of the research study?

It is my aim to use the results from the study for my doctorate in clinical psychology thesis and to possibly publish the work in an academic journal. We will also provide all participants who request one with an information sheet about the results of the research. Your identity will not be revealed in any report or publication.

Who is organising and funding the research? Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South West – Cornwall and Plymouth. This research is sponsored by the University of Exeter. The research has been approved by National Research Ethics Service Committee South West – Cornwall and Plymouth and as such has the support of the University of Exeter, School of Psychology Ethics Committee.

Contact for Further Information

If at any time you would like advice or require further support, please feel free to contact me.

Researchers' Contact Details

Andrew Bromley
Trainee Clinical Psychologist
Washington Singer Building
Perry Road
University of Exeter
Exeter
Devon
EX4 4QG

Dr Phil Yates
Consultant Clinical Psychologist
Mardon Centre
Wonford Rd
Exeter
Devon
EX2 4UD

Thank you for taking the time to read this information

Appendix B: Participant Consent Form

**CONSENT FORM**

Study Title: How do carers for people with a learning disability with dementia experience their role and the support they receive through services?

Chief Investigator: Andrew Bromley

Please initial box

1	I agree to take part in the above study	
2	I confirm that I have read and understand the information sheet dated 09.06.2013 for the above study and have had the opportunity to ask questions.	
3	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
4	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals, from regulatory authorities or from the NHS Trusts, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
5	I give permission for my Doctor or other healthcare professional involved in my care to be contacted about any significant concerns if necessary.	
6	I would like to be sent information about the results of the research when they are available	

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix C: Interview Schedule

Interview Schedule

Carer date of birth: ____/____/____

Gender of carer: Male/Female

Person cared for date of birth: ____/____/____

Gender of person cared for: Male/Female

Relation of carer to person cared for: Parent / Brother/ Sister / Son / Daughter /
Other _____

**Study: How do carers for people with a learning disability with dementia
experience their role and the support they receive through services?**

Introduction: Researcher to Read

“I am interested to hear about your experiences of being a carer, how you perceive your carer role, and your thoughts on support that is out there for supporting carers. I will be asking questions during the interview but please feel free to stop me at any time if you would like to add further information or if you would like a break or to stop the interview. I will be recording the interview so that I can listen back to it later and will also be writing at times during the interview but that is simply to help me to remember some of the information you are giving me. Does this sound ok to you and is it ok for us to begin?”

Part 1: Information about the carer and person with an LD and dementia

“Could you first please tell me how long you have been a carer for?”

“Could you also tell me a little bit about the person or people you care for?”

*If the information isn't provided “So could you tell me whether the person or people you care for has a learning disability and dementia and a little more about that?”

“Could you please tell me how long ago the person you act as carer for was diagnosed with dementia?”

Part 2. Information about carer role, self-care, and dementia diagnosis

“How would you say you find your role as being a carer for someone?”

“What would you say maybe helps in your ability to carry out your role as a carer?”

“What would you say possibly hinders your ability to carry out your role as a carer?”

“Could you tell me whether you have experienced any mental health or significant physical health conditions since you have become a carer?”

*If so, “Are you able to tell me more about this if you have?”

*If so, “Do you feel that these physical/mental health issues you have experienced were related in some way to your role as carer?”

“Do you do anything to help you cope or keep healthy in terms of physically, mentally, and emotionally healthy?”

*If so, “Do you feel any stress associated with the role? Do you do anything to cope with this?”

“Could you talk to me about your experience of when you found out that the person you care for had dementia, how you found out the diagnosis, and any

reflections you have about the time that this happened?”

*If so “Was the information you were given explained adequately, were you given information about support services or given information on how to cope with problems?”

Part 3. Information about carer support services

“I am now going to ask you some questions about support for you as a carer”

“Could you please tell me about support you are aware of that supports carers to do their role”

“Could you tell me whether you access these support services?”

“Could you tell me about any possible barriers, if any, that you perceive to accessing support?”

“Are there any changes that you think would improve these sources of support for carers?”

End of Interview: Researcher to Read

“Thank you for participating in this study”.

Appendix D: NRES Ethics Approval Letter



Health Research Authority

NRES Committee South West - Cornwall & Plymouth

Bristol Research Ethics Committee Centre
Level 3
Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1330

26 June 2013

Dr Leslie Andrew Bromley
Trainee Clinical Psychologist
University of Exeter
School of Psychology, University of Exeter
Exeter
Devon
EX44QG

Dear Dr Bromley

Study title:	A qualitative interview study investigating the experience of carers for people with a learning disability with dementia.
REC reference:	13/SW/0067
Protocol number:	VP/IND
IRAS project ID:	127763

Thank you for your letter of 09 June 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Charlotte Allen, nrescommittee.southwest-cornwall-plymouth@nhs.net.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

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

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

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

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

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

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

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

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

Approved documents

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

Document	Version	Date
Evidence of insurance or indemnity		01 August 2012
Evidence of insurance or indemnity		13 June 2013
Interview Schedules/Topic Guides	2	09 June 2013
Investigator CV		26 February 2013
Letter from Sponsor		
Other: CV - Dr Philip Yates		26 February 2013
Other: Lone Working Policy	1	09 June 2013

Participant Consent Form	2	09 June 2013
Participant Information Sheet	2	09 June 2013
Protocol	2	09 June 2013
REC application	3.4	26 February 2013
Referees or other scientific critique report		26 February 2013
Response to Request for Further Information		09 June 2013

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

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

13/SW/0067	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

Yours sincerely

A handwritten signature in black ink, appearing to read 'PP: CAI' followed by a stylized flourish.

Canon Ian Ainsworth-Smith
Chair

Email: nrescommittee.southwest-cornwall-plymouth@nhs.net

Enclosures: "After ethical review – guidance for
researchers" (*via email*)

Copy to: Ms Gail Seymour

Appendix E: NHS Trust Approval Letter

Research and Development
Wonford House Hospital
Dryden Road
Exeter
EX2 5AF

Tel: 01392 674112
jayneclarke@nhs.net

3 October 2013

Dr Leslie Andrew Bromley
Trainee Clinical Psychologist
University of Exeter
School of Psychology
Exeter
EX4 4QG

Dear Dr Bromley

Study Title: **A qualitative interview study investigating the experience of carers for people with a learning disability with dementia**

Chief Investigator: **Dr Leslie Andrew Bromley**

Sponsor: **University of Exeter**

REC Reference: **13/SW/0067**

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
NRES Approval Letter		26 June 2013
Protocol	2	9 June 2013
Participant Information Sheet	2	9 June 2013
Participant Consent Form	2	9 June 2013
Investigator CV		26 February 2013
Letter from Sponsor		25 February 2013
Interview Schedules/Topic Guides	2	9 June 2013

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP (if applicable), and NHS Trust policies and procedures available at <http://rdweb.exe.nhs.uk/default.asp?a=2&m=0>

Permission is only granted for the activities for which a favourable opinion has been given by the REC (and which have been authorised by the MHRA).

You are reminded that you must report to the R&D office any **adverse event or serious incident**, whether or not you feel it is serious. This requirement is in addition

to informing the Chairman of the Research Ethics Committee which approved the study. The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D Department should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D Department should be notified within the same time frame of notifying the REC and any other regulatory bodies.

All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS. These changes must also be reported to the R&D Department. Likewise any change to the status of a project must also be reported to the R&D Department.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research and requests for study related data. You are also required to submit to the R&D office a **final outcome report** on completion of your study, and to provide interim reports on progress as requested. Should **publications** arise, please send copies to the R&D office, Wonford House for inclusion in the study's R&D file and the Trust's research publications library.

I would also like to remind you of the responsibilities of anyone who conducts research within the NHS, which are:

1. The Data Protection Act requires that you follow the eight principles of 'good information handling' as summarised in the guide for staff.
2. You must be aware of, and comply with Health and Safety standards in relation to your research
3. You must also be aware of NHS Indemnity Arrangements; summary details can be found in Appendix 1.

With best wishes for a successful study.

Yours sincerely



Dr. Peter Aitken
Directorate of Research and Development.

cc CI, sponsor, study coordinator (for CSP inform Lead CLRN and CSPU)

Appendix 1

RESEARCH IN THE NHS: INDEMNITY ARRANGEMENTS

- NHS indemnity covers clinical negligence. It does not cover indemnity for any other liability such as product liability or employers' liability.
- NHS indemnity is Government policy: it is not a statutory obligation.
- NHS indemnity covers negligent harm to patients and volunteers.
- NHS indemnity means that NHS organisations forgo the right to recover costs and damages from their staff in respect of liabilities arising out of clinical negligence (except where that involves criminal or wilfully negligent behaviour).
- Research is a core NHS activity. It is therefore treated in the same way as any other NHS activity in relation to potential liabilities for clinical negligence.
- For all NHS research activity, whether commercial or non-commercial, liability for clinical negligence on the part of NHS staff lies with the health-care professional's NHS or honorary NHS employer.
- Being a research sponsor does not increase potential liability. However, the sponsorship agreement should clarify where liability lies.
- *Where appropriate*, honorary contracts may be used for those involved in research. They provide the opportunity under the NHS organisation's vicarious liability to define the legal arrangements for non-NHS personnel undertaking research.
- An honorary contract extends an NHS employer's responsibilities, but not beyond its existing legal duty of quality and its common-law duty of care.

Appendix F: University of Exeter Psychology Department Ethics Approval

To: Andrew Bromley
From: Cris Burgess
CC: Phil Yates
Re: Application 2012/558 Ethics Committee
Date: February 13, 2015

The School of Psychology Ethics Committee has now discussed your application, **2012/558 – How do carers for people with a learning disability with dementia experience their role and the support they receive through services?** The project has been approved in principle for the duration of your study.

The agreement of the Committee is subject to your compliance with the British Psychological Society Code of Conduct and the University of Exeter procedures for data protection (<http://www.ex.ac.uk/admin/academic/datapro/>). In any correspondence with the Ethics Committee about this application, please quote the reference number above.

I wish you every success with your research.



Cris Burgess
Chair of Psychology Research Ethics Committee

Appendix G: Dissemination Statement

Dissemination Statement

This study will be disseminated in the following ways:

- A presentation of the study findings was shared with a class of trainee clinical psychologists and research staff at the University of Exeter.
- The completed literature review and empirical paper will be available through the University of Exeter's online library resources.
- At the end of each interview the participants were offered the option of receiving a summary of the findings and final themes. A summary of the study findings will be posted to those participants who requested a copy and to the clinical psychologists who assisted in recruitment.
- The literature review will be submitted to the Journal of Intellectual Disability Research for publication.
- The empirical paper will be submitted to the Journal of Intellectual Disability Research for publication.

**Appendix H: Instructions for Authors from Intended Journal:
Journal of Intellectual Disability Research**

Note: The University of Exeter psychology department requirements superseded some guidelines from the intended journal, such as following APA referencing as opposed to Harvard referencing.

Author Guidelines

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.



Individual authors and researchers can now check their work for plagiarism before submission - please click [here](#) for details.

3.1. Getting Started

Content of Author Guidelines: 1. General, 2. Ethical Guidelines, 3. Submission of Manuscripts, 4. Manuscript Types Accepted, 5. Manuscript Format and Structure, 6. After Acceptance.

Relevant Documents: [Colour Work Agreement Form](#)

Useful Websites: [Submission Site](#), [Articles published in The Journal of Intellectual Disability Research](#), [Author Services](#), [Blackwell Publishing's Ethical Guidelines](#), [Guidelines for Figures](#).

1. GENERAL

The Journal of Intellectual Disability Research is devoted exclusively to the scientific study of intellectual disability and publishes papers reporting original observations in this field. The subject matter is broad and includes, but is not restricted to, findings from biological, educational, genetic, medical, psychiatric, psychological and sociological studies, and ethical, philosophical, and legal contributions that increase knowledge on the treatment and prevention of intellectual disability and of associated impairments and disabilities, and/or inform public policy and practice. Such reviews will normally be by invitation. The Journal also publishes Full Reports, Brief Reports, Letters to Editor, and an 'Hypothesis' papers. Submissions for Book Reviews and Announcements are also welcomed.

The Journal of Intellectual Disability Research will feature four Annotation articles each year covering a variety of topics of relevance to the main aims of the journal or topics. Senior researchers, academics and clinicians of recognised standing in their field will be invited to write an Annotation for the journal covering an area that will be negotiated with the Associate Editor, Prof. Chris Oliver, on behalf of the Editorial team. Anyone expert in his/her particular field wishing to submit an uninvited review is advised to seek prior guidance from the Associate Editor.

All papers are assessed by expert referees.

Please read the instructions below carefully for details on the submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication in *The Journal of Intellectual Disability Research*. Authors are encouraged to visit John Wiley & Sons Pte Ltd's [Author Services](#) for further information on the preparation and submission of articles and figures.

2. ETHICAL GUIDELINES

The Journal of Intellectual Disability Research adheres to the ethical guidelines for publication and research summarised below.

2.1. Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the Journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research, the number of authors should not exceed six.

The Journal of Intellectual Disability Research adheres to the definition of authorship set up by The International Committee of Medical Journal Editors (ICMJE). According to the ICMJE authorship criteria should be based on 1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, 2) drafting the article or revising it critically for important intellectual content and 3) final approval of the version to be published. Authors should meet conditions 1, 2 and 3.

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

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interests if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2. Ethical Approvals

Experimental Subjects: experimentation involving human subjects will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net/e/policy/b3.htm) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an

ethical board should also be included. Editors reserve the right to reject papers if there are doubts as to whether appropriate procedures have been used.

All studies using human participants or animal subjects should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material ([http://www.consort-statement.org/mod_product/uploads/CONSORT 2001 checklist.doc](http://www.consort-statement.org/mod_product/uploads/CONSORT_2001_checklist.doc)).

Manuscripts reporting results from a clinical trial must provide the registration number and name of the clinical trial. Clinical trials can be registered in any of the following free, public clinical trials registries: www.clinicaltrials.gov, clinicaltrials-dev.ifpma.org/, isrctn.org/. The clinical trial registration number and name of the trial register will be published with the paper.

The Journal of Intellectual Disability Research encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public clinical trials registries: www.clinicaltrials.gov, clinicaltrials-dev.ifpma.org/, isrctn.org/. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent, ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflicts of interest) will be published under a separate heading entitled 'Conflict of Interests'.

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

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

Source of Funding: Authors are required to specify the source of funding for their

research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

2.5 Appeal of Decision

Authors who wish to appeal the decision on their submitted paper may do so by e-mailing the Editorial Office with a detailed explanation for why they find reasons to appeal the decision.

2.6 Permissions

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publishers.

2.7 Copyright Assignment

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:

CTA Terms and Conditions http://authorservices.wiley.com/bauthor/faqs_copyright.asp

2.8 OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

Creative Commons Attribution License OAA

Creative Commons Attribution Non-Commercial License OAA

Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services

http://authorservices.wiley.com/bauthor/faqs_copyright.asp and visit <http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html>.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit:

<http://www.wiley.com/go/funderstatement>.

3. SUBMISSION OF MANUSCRIPTS

Manuscripts should be submitted electronically via the online submission site <http://mc.manuscriptcentral.com/jidr>. The use of an online submission and peer review site enables immediate distribution of manuscripts and consequentially speeds up the review process. It also allows authors to track the status of their own manuscripts. Complete instructions for submitting a paper are available online and below. Further assistance can be obtained from Ms Sue M Hampton-Matthews at the Editorial Office of JIDR, Second Floor, Douglas House, 18b Trumpington Road, Cambridge, CB2 2AH, UK +44 1223 746 124; e-mail: shm44@medschl.cam.ac.uk.

- Launch your web browser (supported browsers include Internet Explorer 6 or higher, Netscape 7.0, 7.1, or 7.2, Safari 1.2.4, or Firefox 1.0.4) and go to the journal's online Submission Site: <http://mc.manuscriptcentral.com/jidr>
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All manuscripts submitted to The Journal of Intellectual Disability Research will be reviewed by two experts in the field. The Journal of Intellectual Disability Research uses double-blinded review. The names of the reviewers will thus not be disclosed to the author submitting a paper and the name(s) of the author(s) will not be disclosed to the reviewers.

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The Journal of Intellectual Disability Research attempts to keep the review process as short as possible to enable rapid publication of new scientific data. In order to facilitate this process, please suggest the names and current e-mail addresses of 1 potential international reviewer whom you consider capable of reviewing your manuscript. In addition to your choice the journal editor will choose one or two reviewers as well.

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Original Research Article The main text should proceed through sections of Abstract, Introduction, Methods, Results, and Discussion.

Full Reports of up to 4,500 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions.

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It aims to outline a significant advance in thinking that is testable and which challenges previously held concepts and theoretical perspectives.

5. MANUSCRIPT FORMAT AND STRUCTURE

5.1. Format

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

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Please note that 'intellectual disability', as used in the Journal, includes those conditions labelled mental deficiency, mental handicap, intellectual disability and mental retardation in some countries.

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All manuscripts submitted to *The Journal of Intellectual Disability Research* should include: Title, Keywords, structured Abstract, Main Text (divided by appropriate sub headings) and References.

Title Page: Please remember that **peer-review is double-blind**, so that neither authors nor reviewers know each others' identity. Therefore, **no identifying details of the authors or their institutions must appear in the submitted manuscript; author details should be entered as part of the online submission process.** However, a 'Title Page' must be submitted as part of the submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

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The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic Markers in Human Blood. Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* **24**, 137- 41.
- Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: *Life Course Perspectives on Adulthood and Old Age* (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

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Tables: Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, Table 2, etc., and give a short caption.

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