

Title:

Fathers of adults who have a learning disability: roles, needs and concerns

Accessible summary:

- ☐ This study asked fathers of adults who have a learning disability about their experiences, what helps them and any worries they may have.
- ☐ Fathers reported different experiences of being a father to an adult with a learning disability and talked about things that were helpful, such as their wives, grandparents, having information and hobbies.
- ☐ Fathers were worried about the person who has a learning disability in the future.
- ☐ Fathers can be important in supporting people who have a learning disability throughout their lives.

Abstract:

Background: There is little research that specifically relates to fathers of adults with a learning disability despite the social expectation that fathers will provide a supportive role over the lifespan.

Methods: Semi-structured interviews were carried out with seven fathers of adults with a learning disability to explore their roles, needs and concerns. Data was analysed using a framework associated with Interpretative Phenomenological Analysis (IPA).

Results: Themes arising demonstrate that fathers were shocked at the diagnosis of learning disability but usually reported adaptation over time. The impact of learning disability upon men's lives, their perception of their adult child and the roles they assumed were varied. Fathers valued support from

wives and grandparents; having knowledge and interests and work type roles. All fathers were concerned about the future yet comprehensive futures planning was lacking. Some fathers reported difficulties in being emotionally open, and referred to societal stereotypes. Fathers valued positive support from service providers; however this relationship was often in conflict.

Conclusion: Although mothers are often the main carers for adults with a learning disability, fathers can make a significant contribution. The findings presented here support the results of previous studies regarding paternal response to learning disability and varied impact upon men's lives. Identified support strategies include leisure interests, volunteer/ work roles, having information and support from wives and grandparents. Ongoing concerns incorporate the future and ambivalent relationships with service providers, which could have a negative impact upon the individual who has a learning disability.

Key words:

Fathers; adults; learning disability; roles; needs; concerns.

Introduction

There is an expectation within contemporary society that fathers will maintain an active support role in the care of their children (Towers 2009). They are reported to be significant in the overall development of their children and in the wellbeing of the family system (Flippin and Crais, 2011). Although there is research that relates to fathers of children within the field of learning disability, there is very little that is specific to fathers of adults or their long term needs (Gore 2010). This gap is significant against a context of increased social expectations of men as carers, changes in family composition, for example single parents and same gender relationships, increased demand upon families to provide an extended care role over the life course and diminished public resources (Taylor and Hodapp, 2012).

Existing research on parents of adults who have a learning disability tends to focus upon mothers (Yoong and Koritsas 2012) and therefore issues that are father specific rarely arise. Of the father specific research, much is over ten years old which limits currency, and studies that include fathers of adults aged 18 and over are often cross sectional, focus upon psychological wellbeing and employ a quantitative methodology (Davys et al 2016). Due then to the lack of research on fathers of adults and their long-term concerns and needs, an in-depth qualitative study is justified.

Review of the literature:

Within the literature, men reportedly experience caregiving differently to women (Di Novi et al 2015) and lack skills and experience in caregiving (Walker 2010). They are less likely to seek, and therefore receive support, to discuss difficulties or actively maintain their own health and wellbeing. They are also reported to have smaller social support networks. Fathers of adults who have a learning disability report their concerns about the future, the level and quality of service provision, and the need for time away from a care role (Carers UK 2017, Mencap 2017). Such issues may negatively impact the health and wellbeing of fathers of adults who have a learning disability (Thoits 2010). From recent literature review that includes fathers of people who have a learning disability up to the age of 22 years (Davys et al 2016), the following issues were raised.

Stress is a common theme within the literature and is often reported after initial diagnosis (Rivard and Mastel-Smith 2014; Bostrom and Broberg 2014). Many studies do however report adjustment and a reduction in stress and depression over time (Baumann and Braddick 1999) yet the findings are diverse. Some studies report higher rates of depression and lower satisfaction within family relationships for fathers in the presence of learning disability compared with families where children had a physical

disability or were typically developing (Cummings 1976). Other studies report no significant difference in stress levels (Rodrigue et al. 1992) or even enhanced psychological wellbeing (Boyratz and Sayger 2011). It is important to note that some fathers report pleasure from the presence of their children, alongside the development of attributes such as patience and a deeper understanding of people who have a disability (Baumann and Braddick 1999). Associated with stress is the issue of interpersonal relationships and again, research findings are contradictory. Some studies note decreased satisfaction in family relationships (Cummings 1976), whilst others refer to varied satisfaction (Baumann and Braddick, 1999), no significant difference in family and marital relationships (Hornby 1995), or report a closer marital relationship compared to typically developing families (Rivard and Mastel-Smith 2014).

Although mothers are typically the main caregivers, some fathers do maintain a significant care role, especially when children are young (MacDonald and Hastings 2010) which may be associated with stress. For fathers who have a work role, this is portrayed in the literature as both a source of stress and a coping strategy. Fathers in full time employment can encounter difficulties such as loss of earnings and reduced work prospects (Carpenter and Towers 2008, Wright, Crettenden and Skinner 2015). Fathers also report difficulty in attending meetings about their child due to work commitments (Ly and Goldberg 2014). Despite work related stress however, some men utilise work as a coping strategy to remediate their situation (Bray et al 1995).

A further potential source of stress for fathers is their relationship with service and educational providers, which is reportedly diverse. There are reports that services focus their attention upon mothers, which leads to fathers feeling excluded (Rivard and Mastel-Smith 2014, Mueller and Buckley 2014a, 2014b). Other studies present paternal relationships with service providers as on a spectrum, where some note inclusion and positive interaction yet others feel ignored (Carpenter and Towers 2008). In order to support fathers, service providers have been called upon to consider the type and

timing of service delivery in order to facilitate fathers' attendance and to give due respect to their role (Ly and Goldberg 2014).

Service provision to meet fathers' needs and concerns is an under-developed area of research. Various studies refer to fathers seeking knowledge and information to better support their family (Bostrom and Broberg 2014). Within these studies, fathers sought information via support groups, health and social care professionals, forums and the Internet. Such information seeking has been described as a positive coping strategy by Rodrigue et al (1992) although less positive strategies, such as the use of alcohol, avoidance of the home situation and distancing are also reported (Houser and Seligman 1991; Bray et al 1995). In terms of concerns, fathers report apprehension regarding the long-term accommodation needs and continued wellbeing of their offspring (Rivard and Mastel-Smith 2014; Baumann and Braddick 1999).

In view of the lack of research specific to fathers of adults who have a learning disability, their needs and concerns, this study aims to provide a deep exploration of the role, needs and concerns of men in this situation, and to report their lived experience.

Methods

Design:

An Interpretative Phenomenological Analysis (IPA) methodology (Smith and Osborn 2003) was utilized within this study. As a methodology, it is transparent regarding the subjective interpretation that the researcher brings to bear upon the analysis and reporting of results (Lopez and Willis 2004). This approach allows individuals who have experience of a particular phenomenon to voice their lived

experience, and is an appropriate methodology for deep exploration within a small homogenous group (Smith et al 2009). This is aligned with the aims of this study, which refer to providing an exploration and in-depth understanding of the experience of fathers of adults who have a learning disability.

Data collection:

Before any data was collected, ethical approval was gained from The University of Salford. Gatekeeper co-operation was sought from learning disability self-help organisations in the Greater Manchester area to gain access to fathers of adults aged 20 or over who have a learning disability. Gatekeeper organisations passed on study information sheets to potential participants, which contained researcher contact details so that individuals could self-select their participation. Two repeat requests for organisations to send out study details were made. Upon contact with the researcher, further reiteration of the study aims, interview process and consent issues were discussed. Where participants agreed to proceed, a time and place to carry out the interview was arranged. Nine fathers contacted the researchers and seven agreed to participate.

In line with the principles of IPA, one-to-one semi-structured interviews were carried out to provide deep exploration and individual perspectives within a small defined group (Smith and Osborn 2003). Before each interview, written consent was gained. Questions related to father's involvement with their offspring, concerns they may have and anything they felt would support them in their role as a father (Appendix A). The interviews lasted on average 75 minutes and all were audio taped and transcribed. The mean age of the fathers was 62 and the mean age of the person with a learning disability was 32. Six fathers were married and one was a widower. Further sample details can be found in Table 1. Similarity in fathers' ages, employment status and child characteristics are noted which further supports

the use of IPA as a methodology. Interviews took place in a university setting or the participant's own home depending upon preference.

Analysis:

IPA accepts the dynamic process of interpretation between researcher and participant, and although there is no finite method of analysis, general principles suggested by Smith and Osborn (2008) were followed. Each audio recording was transcribed verbatim and after multiple independent review by two researchers, key points were noted in the right-hand margin. After further review, emergent themes and their association with each other were noted in the left-hand margin; which allowed superordinate and subordinate themes to be identified (Smith et al 2009). Superordinate and subordinate themes for each interview were then examined and compared. Superordinate and corresponding subordinate themes were recorded in a theme and evidence chart for each interview, with supporting participant quotes included as evidence of the presence of the themes identified. The third researcher reviewed all theme and evidence charts to support trustworthiness and credibility. Superordinate themes present in all seven interviews and subordinate themes present in a minimum of 3 of the 7 interviews are presented.

Findings:

Seven superordinate themes emerged from the interviews: fathers' response to learning disability; impact of learning disability upon fathers; fathers' perceptions of the person who has a learning disability; fathers' roles; supportive contexts; the future; and fathers' comments about men.

Key theme 1: Fathers' response to learning disability

All fathers were aware of delayed development by school age and a bereavement response was reported in six of the seven interviews, alongside reference to fear and anxiety. Two elements of grief were apparent, one related to lost opportunities for their child, and the other to the lost hopes of the father.

Interview 7 "you go through all these things like he will never, he will never read, he might never walk, which is nuts, but you think them....And I'm saying even ridiculous things like, bizarre things like oh well that pram was a waste of time, of money, it was almost like a bereavement you see",

Interview 4 "I felt the usual things, you know, why me. Because anyone first starting off, I had great expectations of what I was wanting from my child, and that has gone".

Despite the references to bereavement and loss, 3 fathers (3,4,7,) mentioned adjustment, with only 1 father (6) referring to ongoing sadness. A positive response to learning disability was also noted, for the father in interview 1, there was "major relief" that his child was not dying, in interview 3, the father refers to becoming actively involved in services and rearranging his life to accommodate the learning disability, whilst in interview 7, the father says that the diagnosis made him more involved.

Key theme 2: Impact of learning disability upon the father:

Both positive and negative impacts of learning disability were reported, yet significantly more negative than positive impacts were recorded.

Positive comments were made by five fathers, with some comments related to the positive attributes of the individual, for example that they are good company or brought joy and humour to the father's life.

In a number of instances opportunities that may not otherwise have arisen were referred to, which could be interpreted as positive. For example in interviews 1 and 5, the fathers took an active role in campaigning and voluntary work, which brought them satisfaction, and in interview 4, the father “pushed” himself at work to enhance his learning.

Interview 5 “I’m a local campaigner if you will for equality of healthcare for people with learning disabilities....And I really enjoy doing that...”

The most frequently occurring negative impact of learning disability was feelings such as worry, stress, depression and anger. Worry was associated with the health and wellbeing of the person regarding their safety and the future. Other negative impacts included restrictions in finance and social life, an ongoing care role, conflict at work and marital disruption.

Interview 5 “...there was a while when he was in his mid-teens that I felt as if I was the third person in the relationship and I’d go to work and I’d come home and I was being ignored... We actually separated for a couple of months and then thought this is stupid what are we doing? And got back together and we said let’s try and work this out”.

In most instances, learning disability impacted upon the fathers’ work situation. All 7 participants referred to a work role with one father maintaining a volunteer role. Fathers in five interviews worked full time until retirement, however four had health issues (physical and psychological), which contributed to early retirement. Father 3 moved from full time to part time work to better suit the needs of his offspring, and two participants reported conflict at work on account of the learning disability.

Interview 6 “the Director really didn’t believe it was coincidence (situation with person who has a learning disability)...and he basically said..., you either work with us or you’re against us. ...They reviewed that and one job went....Mine, what a surprise”.

Key theme 3: Fathers’ perceptions of the person who has a learning disability.

All fathers talked about their adult child in terms of their abilities, attributes or needs. Six fathers referred to positive aspects, for example ability to read or hold down a job or presence of good social skills (interviews 1,3,4,5,7), and 5 fathers made comment about positive attributes, such as being affable, loving or a nice person.

Interview 6 “(Son)’s a very nice person and if you, if you get to know him, he’s very nice... he’s got a great sense of humor, he can just be very amusing, very pleasant to be with...”

Fathers did however spend more time commenting upon the needs of their offspring than discussing their attributes. All fathers stated that the individual needed support to manage their health and well being, ranging from major issues such as epilepsy, to more minor issues.

Interview 2 “With his epilepsy as well he has drop down seizures, he doesn't know they're coming and he just falls. Then we have to give him Midazolam ... We've been told that one of these days he might not come out of the seizure”.

All fathers claimed that their children needed help with finances and most referred to vulnerability in terms of physical, sexual and financial safety, alongside some degree of support with personal care. Other difficulties raised were communication and behaviour and most fathers noted their adult children needed support on multiple levels.

Key theme 4: Fathers' roles

Six fathers reported engagement in tasks during childhood such as feeding, personal care or support with a night time sleep routine, however some only undertook this role if their wife was unavailable. In adulthood, 5 fathers provided support with personal care tasks, yet in most instances, apart from the father who was a widower, the wife was still the main carer. A supportive / protector role towards the adult child or wife was mentioned in three interviews, and three fathers reported multiple care roles.

Five fathers held ongoing volunteer / campaigner / advisory roles which had lasted many years and often had links with learning disability either directly, for example school governor, or indirectly, such as supporting carers. Linked with the key theme of Supportive contexts, four participants had an information seeker role, which suggests that having knowledge or information is useful to fathers.

Interview 5 "... when he was diagnosed with the diabetes. I put myself on a course for people with type two diabetes. So that I could understand the type of diet he should be on".

Key theme 5: Supportive contexts

All participants made both positive and negative comments about services, with more negative than positive comments made. Positive comments included services "getting it right" and that some staff are "good", whilst negative comments referred to services as "lacking", "not enough" and "not appropriate". Additional complaints were that services ignore the needs of fathers and the person who has a learning disability. The word "fight" was used explicitly in reference to service providers in four interviews and words such as "conflict", "tension", "argument", and "battles" provide further indication of difficulty.

All participants noted that family and peer support, especially from wives and grandparents was helpful. The mother of the person who has a learning disability was the main carer in 6 of the 7 interviews throughout childhood, which can be viewed as a significant help for fathers. For 6 participants, the wife's main carer role allowed them to work, which is discussed further under the key theme; Impact of the learning disability upon the father.

Interview 2 (in adulthood) "(Wife) is 80% (main care provider) ..Yes. Without a doubt... Yeah, more than me with everything. She gets in the shower with him still now; he sleeps with (Wife) you see. He's always slept with (Wife)... I've not slept with (Wife) for 22 years.... I think I've been dead lucky with (Wife), seriously...Yeah, the way she looks after him. I used to play golf and I knew that he was alright when he was with (Wife)".

Wives were seen to have a greater role than fathers in decision making or liaison with services in four interviews, which could again be considered supportive, and three wives were described as "homemaker" which might also be helpful. Four fathers made specific reference to help provided by grandparents.

Four participants valued having information or knowledge and the importance of knowledge was further referred to within the key theme of Fathers' roles. The use of hobbies, interests, employment / voluntary roles were considered worthwhile by four men, with one father referring to work and a volunteer role as a coping strategy and distraction from the home situation.

Interview 6 'and after five minutes (in the voluntary setting) you'd think, actually I haven't got any problems me, it's these poor buggers have got the problems, not me, I'm alright and it was an escape, it was an escape, it allowed me time to switch off, put on different focuses and, yeah, they were helping me rather than vice versa.'

Key theme 6: The future:

Concern about the future was prevalent throughout all the interviews and took the form of worry about what would happen when parents were no longer able to care (1,4,5,7), the health and wellbeing of the adult child (2,3,4,7), standards of care (2,3,5,7) and accommodation (1,6,7). In terms of futures planning, detail was lacking across the interviews and even where a tenancy agreement was in place (interview 7) or where a named person had agreed to provide care (interview 2), there was some degree of uncertainty and practicalities were unanswered

Interview 6 'When, when he was a young teenager we'd said by the time I was 60 or by the time he was 30, he needed to be in his future. He needed to be wherever he was going to be because there would be nothing worse than him waking up one day to find you dead... that all needed to be settled. He's (in his 30`s) now, I'm (in 60`s) we're nowhere near, nowhere near.'

Four participants referred to the future support expectations of their family and this varied from expecting them to be involved to being unclear about what would happen, all of which reinforces the uncertainty around futures planning.

Key theme 7: Fathers' comments about men

The fathers made comments about men that can be summarised under the headings: groups and services; marriage and learning disability; emotions and the male role. Within the subordinate theme of groups and services, three fathers claimed that men are uncomfortable in group situations. The father in interview 7 stated that groups do not meet the needs of fathers, and that men learn about learning disability through women. This idea is reiterated in interview 6, however here the father makes the

point that men learn information from their wives because services do not communicate directly with fathers.

Five fathers expressed the view that learning disability puts a strain upon a marriage, and some expressed opinions about what would help a marriage work in this situation, for example partners communicating, men having the opportunity to express difficulties, and that both partners need access to information and a shared approach to the situation. The need for stereotypical roles of the father working and the mother being the main carer were also advised.

Emotions, and the male role are intertwined. Fathers in three interviews commented that men find it difficult to be emotionally open with other men, which may explain some of the comments made about men and groups. When participant 7 was asked why he would not discuss difficulties with another man, he replied that other people could not comprehend the issues and are disinterested. The reluctance of fathers to be emotionally open, could be associated with the perceived “male role” within society. Fathers in two interviews talked about men feeling that they have to be a “rock”, a “breadwinner” and “macho”, and for some men, acknowledgement of learning disability within their children may be considered a sign of fault or weakness on their part.

Discussion:

The findings from this small scale in-depth study demonstrate alignment with existing research. Such similarities may suggest that fathers perceive continuity of experience over the life course, however the lack of research into fathers of adults makes this theoretical perspective difficult to evidence and supports the call for further research in this field. Similarity in findings include paternal response of shock and bereavement followed by acceptance, in response to a diagnosis of learning disability (Bostrom and Broberg 2014) and the varied impact of learning disability upon fathers’ lives (Hornby

1992; Rivard and Mastel-Smith 2014). Fathers in this study however devoted more time to talking about the difficulties of their situation rather than positive aspects, and a number of participant quotes referred back to the person with a learning disability's childhood. This could suggest that despite reported acceptance of the situation, the presence of learning disability remains a matter of on-going stress and concern for fathers throughout the life course. The results presented here also support the view that fathers may experience difficulty in the work place on account of their situation (Ly and Goldberg 2014) yet a work role may equally serve as a coping strategy (Bray et al 1995). Similarities between the findings of this study and previous research are also present regarding the value fathers place on information (Rivard and Mastel-Smith 2014), their concern about the future (Bibby 2012) and for some men, the difficulty they have in being emotionally open (Walker 2010).

However, in contrast to previous studies, findings from this in-depth exploration of fathers of adults illuminate the significant value they place on support from their wives and parents. This is an important consideration for services as fathers will ultimately lose the support of their parents as aging occurs and marital or relationship status may change. Change in these support networks could lead to increased pressure on fathers, and services may need to support men in these situations. Also of relevance is the value of a hobby, interest or volunteer role, which could potentially mitigate against stress and support paternal health and wellbeing, if the role holds meaning and purpose for the father (Fossey and Newton Scanlan, 2014). Furthermore, the presence of paternal concern for the future, which is apparent in studies that include fathers of children and young adults, has been shown through these findings to remain a source of on-going stress and anxiety as adult children age. Despite this concern, there remains a lack of futures planning (Bibby 2012), which could be a long-term stressor that negatively impacts upon the health of fathers (Thoits 2010) and ultimately could have an adverse effect upon adults who have a learning disability.

It is acknowledged that the main limitation of this study is the small sample size and associated difficulty in generalisation of results. It would be useful to compare the findings to future studies in this field. From the results presented here however and with consideration of previous research (Davys et al 2016) and guidelines from organisations such as the Foundation for People with Learning Disabilities (2009); providers from all backgrounds need to review service delivery. It is suggested that fathers should be involved in the planning, provision and audit of learning disability services, and that their role is acknowledged. This could incorporate using inclusive written and oral communication and providing services at times when fathers are available. Fathers also value knowledge and information that is condition related or provides practical advice for their individual circumstances. Fathers may benefit from information sharing events, for example related to flexible working legislation, on either a group or individual basis. They may benefit from meeting other fathers in a similar situation, and appreciate the opportunity to acquire skills relevant to their son/daughter, for example how to manage specific behaviors. Support to manage stress and personal health issues for example by regular health checks, information on futures planning and overall respect for the father role across the life course are also required.

Conclusion:

The results of this study confirm that fathers can and do have a significant role in the lives of adults who have a learning disability across the life course. The findings presented here support and develop the results of previous studies in relation to paternal response to learning disability, its varied impact upon men's lives, workplace difficulties and the value of information. The findings provided new information on the significance of support received from their wives and parents, the value of meaningful work, leisure and volunteer roles in paternal wellbeing, and fathers' on going concern for the future. Service providers need to recognise, value and work towards meeting the needs of fathers, in order to ultimately support the needs of the individual who has a learning disability.

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Appendix A

Interview Guide:

1. Can you tell me a little about yourself and your family situation?
2. Can you tell me about your son / daughter who has a learning disability? (E.g. age, where they live, diagnosis, care / support required)
3. How did you find out that your son / daughter had a learning disability?
4. What was your response to this news?
4. What sort of contact or involvement did you have with them when they were children / teenagers/ young adults? (Consider frequency of involvement)
5. What sort of contact or involvement do you have with them now? (Consider frequency of involvement)
6. Do you have any concerns about your son / daughter who has a learning disability? If so what are your concerns?
7. If you think about the past or into the future, is there anything that would help you in being a father to an adult who has a learning disability?

Table 1 Father details

Participant father	Father Age	Marital status	Work situation	Family situation	Person who has a learning disability
1	60-70	Married	Mainly unpaid campaign work	Lives with wife and daughter who has learning disability. Other typically developing children.	Female 30-40 years old. Requires some support with personal and domestic tasks.
2	60-70	Married (2 nd marriage to mother of son with learning disability)	Retired to support wife with son's care	Lives with wife and son who has learning disability. Typically developing children from 1 st marriage	Male 20-30 years. Requires support with all personal and domestic tasks.
3	40-50	Married	Works part time	Lives with wife and son who has learning disability. Other typically developing child.	Male 20-30 years. Requires support with all personal and domestic tasks.
4	60-70	Married	Retired on health grounds	Lives with wife and son who has learning disability. No other children.	Male 40-50 years. Independent in most personal and domestic tasks.
5	60-70	Widower (2 nd marriage to mother of son with learning disability)	Retired on health grounds	Lives with son who has learning disability. Typically developing children from 1 st marriage.	Male 30-40 years. Requires support with most personal and domestic tasks.
6	60-70	Married	Retired on health grounds	Lives with wife and son who has learning disability. Other typically developing child.	Male 30-40 years. Requires support with all personal and domestic tasks.
7	60-70	Married	Retired	Lives with wife.	Male 40-50 years. Lives in community with support.

