Parental experiences of caring for a child with intellectual disabilities: A UK perspective

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Abstract
A structured literature search and thematic analysis of six research articles relating to stress and parenting of a child with an intellectual disability in the United Kingdom identified four key themes: impact upon families, service provision and support networks, coping and transition. The findings identified that parenting a child with an intellectual disability is not always a negative role; it is a role that parents find both rewarding and empowering. However, the findings of the literature review primarily related to mothers of children with an intellectual disability with very little focus on the experiences of fathers.

Keywords
child, intellectual disabilities, literature review, parenting, stress

Introduction
It is estimated that 985,000 people in England have an intellectual disability (2% of the general population); of these, approximately 16% are children and 30% live in single parent households (Emerson and Hatton, 2008). It is family members, in particular mothers, who provide the most support to their children with an intellectual disability, leaving them more likely to experience
stress (McConkey et al., 2006). This may in turn affect the health of both child and parent and may impact upon family relationships. Hassall et al. (2005) suggest that the parents of a child with an intellectual disability are significantly more likely to experience parenting stress than parents of children who do not. Furthermore, their levels of stress are affected by levels of formal support from professionals and social support from partners, family members and friends (Hassall et al., 2005). Research by McConkey et al. (2004) has shown that services do not always address the needs of parents and do not offer continual support; some families felt that services did not always fit their individual needs. The most effective approaches to meet the needs of children with intellectual disabilities and their families is described by King et al. (2003) as one that is family-centred in nature and one that adapts to fit with the needs of both the child and his or her family. The aim of this literature review is to explore the views and experiences of parents caring for children with intellectual disabilities, the impact upon their family and the impact of service provision on their experiences. Although this is a subject area that has been covered many times, it is one that continues to be important as it is a subject area that will always be relevant to families of children with intellectual disabilities. This article focuses on the United Kingdom primarily due to differences in services provision, in part due to different care systems but also as the support that is available impacts upon many aspects of parental experiences.

Literature review

Whilst exploring the literature on the experiences and stresses of parents who are caring for a child with an intellectual disability, it was important to first consider the definition of a child. For the purposes of this literature review, the definition of a child will be reflective of the Children Act 2004, which means a person under the age of 20 years if they have an intellectual disability.

Method

A systematic search (Hek et al., 2000) was carried out between September and December 2011 using the Cumulative Index to Nursing and Allied Health Literature (CINAHL); however, results were limited so this search was extended using EBSCOhost. This allowed for the searching of multiple databases including Academic Search Premier, CINAHL with full text, Education Resources Information Centre, Medline, PsycArticles, PsycBooks, PsycInfo and Education Research Complete. A further database, Scopus, was also searched due to its relevance in nursing research along with the British Nursing Index and EMBASE, the Excerta Medica Database. Search terms included keywords such as ‘child “AND” intellectual disabilit*’, ‘child “AND” intellectual disabilit* AND parent’, ‘parent AND intellectual disabilit* AND experiences’ and ‘parent AND intellectual disabilit* AND stress’. All searches included the word ‘AND’ as a Boolean operator (Ely and Scott, 2007) and the use of truncation (Harvard, 2007) in order to expand the search, for example, intellectual disabilit* ensured the inclusion of studies including the term intellectual disability and intellectual disabilities. A further inclusion criterion was that studies that focused on the United Kingdom as policies and service systems mean that support available for parents may vary compared with other countries due to the UK’s National Health Service. Although the review of the literature focuses on the United Kingdom, the findings may be useful in offering a comparison with international systems of support.

The results were narrowed by applying inclusion criteria such as date, a range of 2002–2012 was selected as the Department of Health (2001) report ‘Family Matters: Counting Families In’ represented a synthesis and review of literature prior to 2001 and it was felt that literature
post-2001 would be the most relevant to a current literature review. Further inclusion criteria limited results to primary research only; Kennedy (2003) identified that primary research evidence is more esteemed and respected than other sources in providing the best quality and most effective health and social care. Randolph (2009) suggests that electronic searches lead to the retrieval of around 10% of articles that help to achieve an exhaustive review and recommends that reference lists from selected articles are examined to identify any further relevant research. This method of data gathering should be continued until no new relevant articles are found, which is known as point saturation (Bowen, 2008). This approach was followed but elicited no additional results relevant to the study with the exception of duplicate findings.

Results

The systematic search identified 514 research articles of which the titles and abstracts were examined. From this, 13 articles appeared to meet the inclusion criteria based upon the information provided in the abstracts. Upon further scrutiny and after reading the full texts of 13 shortlisted articles, it was clear that not all fully met the inclusion criteria so some were excluded from use in the literature review. Articles were excluded as they explored parent training programmes or were focused on the views of parenting children as adults. Although excluded they have been used within the body of the review for the purposes of background and supporting information. This left six primary research articles (Wallace and Wray, 2006) dating from 2005 to 2010 for inclusion in the literature review (see Appendix 1). These were then subjected to analysis using the preview, question, read, summarise (PQRS) system (Cronin et al., 2008) in order to form the basis of the literature review. Using this framework, the articles were critically appraised to explore their levels of robustness in relation to the methodological approaches and levels of trustworthiness of the findings. Four of the articles were of a qualitative nature and varied between their data collection tools, with Todd and Jones (2005) using in-depth interviews, Johnson et al. (2006) and Towers and Swift (2006) using semi-structured interviews and Johnson et al. (2006) using grounded theory methods. Grounded theory was used within their study as it offers a detailed analysis of the findings and helps to develop theories about the sample that are being studied (Chamberlain et al., 2004; Strauss and Corbin, 1990), hence, offering depth to views of the fathers who were interviewed. Catherall and Iphofen (2006) opted for a phenomenological approach using both unstructured and semi-structured interviews. Phenomenology is a philosophical approach exploring the views of people’s subjective experiences in a particular area (Fulcher and Scott, 2007), meaning that although the views do not offer breadth in terms of generalisability, they do offer a depth into the lived experiences of individuals. Holloway and Wheeler (2003) suggest that interviews are perhaps the most common and useful methods of data collection in qualitative research and point out that there should be evidence of how themes or questions were derived in semi-structured interviews. Also that the initial question used within in-depth or unstructured interviews should be apparent and clearly linked to the purpose of the study. This was demonstrated in each of the articles, which showed strengths within them. A quantitative approach was used by Kenny and McGilloway (2007), Howie-Davies and McKenzie (2007) and Mansell and Wilson (2010) in the form of postal questionnaires offering an alternative view into the experiences of parents caring for a child with an intellectual disability. This approach is useful within this literature review in terms of comparing qualitative and quantitative findings; this was apparent within the study by Kenny and McGilloway (2007) and Mansell and Wilson (2010) who used triangulation in their
study, offering qualitative findings from open-ended questionnaires and quantitative findings from surveys offering both depth and breadth to the findings (Patton, 2002).

Discussion

Common themes were identified across the research, which Dixon et al. (2004) identify as important when synthesising the results of research for a literature review. The themes were distilled into four key themes that formed the basis for thematic analysis, namely impact upon the family, service provision and support networks, transition and coping.

Impact upon the family

Whilst exploring the impact of a child’s intellectual disability on the family, many common subthemes were identified, namely the impact on siblings and impact on parents and social isolation. In terms of the impact on siblings, there has been many published research that looks specifically at their views (Hames, 2008; Knott et al., 2007; Sykes, 2010). However, in the context of research that explores the views from a parental perspective, Johnson et al. (2006) in their research into maternal experiences found that mothers recognised that siblings are often affected by the child with the disability. For example, some parents talked about differing standards of acceptable behaviour for the child with the disability compared with their siblings. Others talked about the fact that activities revolved around the child with disabilities and how it had a negative impact on their other children. Catherall and Iphofen (2006) also found that siblings were significantly affected by their siblings’ disability. One parent was quoted as saying that her daughter can only have friends around to visit when the child with the disability is out as it was less problematic. This study highlighted that siblings play a significant role in offering both physical and emotional support to their parents. Due to the small sample size of 14 parents (7 couples) in this study, it is acknowledged that the results are not necessarily generalizable; however, a further qualitative study carried out in a different geographic area reported similar findings. Todd and Jones (2005) in their study of the transitions involved in parenting a child with intellectual disabilities identified that parents relied upon siblings for informal support, which they found useful in terms of maintaining employment and day-to-day activities. Previous research by Todd and Shearn (1996) and Shearn and Todd (2000) suggested that this was a result of difficulties in accessing formal support services. Although parents recognised that this may place a burden on their children (Catherall and Iphofen, 2006; Johnson et al., 2006), some parents expressed a concern that as the older children left home, they would lose one of their greatest sources of support (Todd and Jones, 2005).

Johnson et al. (2006) carried out semi-structured interviews with 18 separate parents whose children had intellectual disabilities in order to gain an insight into the complex experiences of their role (Baker, 2007). The sample was selected from the Family Fund database that records the details of families of disabled children who have applied for financial support, and Johnson et al. (2006) acknowledge that this approach to sampling may introduce a degree of sampling bias (Cuddeback et al., 2004) and may not reflect the views of all parents of children with intellectual disabilities. As the Family Fund is a charity that offers means tested funding for families on low incomes (Family Fund, 2001), this potentially restricts the sample to only families from a lower socioeconomic background. However, in terms of the purpose of the study, the views of the parents are important and beneficial to the agencies that support these families; as Brink and Wood (2001) point out, researching the views of a population can help to improve services for that group.
Johnson et al. (2006) explored the views of the main parents, defined as the person who provided the most day-to-day care in their studies and identified that many parents experience conflict with their partners, siblings of the child with the disability, their own parents and with professionals. Parents reported that much of the conflict emanated from the child’s problem behaviours and differing approaches in managing these behaviours (Johnson et al., 2006). This was echoed in findings by Catherall and Iphofen (2006) in their phenomenological-based research especially of two fathers who felt that their contributions were not adequate and that they were more of a hindrance than a help. Parents also expressed their frustrations at the lack of available time they had to spend together without their child (Catherall and Iphofen, 2006) and the time that they did have was a precious commodity (Todd and Jones, 2005). Findings by Towers and Swift (2006) looked at the views of 21 fathers of children with intellectual disabilities and found that fathers experience high levels of tiredness due to their full-time job to support the family and then going home and helping out with the caring and household tasks. This may lead to a degree of resentment between parents and the levels of tiredness may impact on the quality of time that they have alone together. Some fathers who were interviewed expressed resentment at the fact they were sharing the caring responsibilities with their partners but felt that it was not acknowledged by professionals as it was outside of working hours (Towers and Swift, 2006). Arguably, this affected their confidence in terms of their role being acknowledged and valued.

In an exploratory study of parental strain and coping, Kenny and McGilloway (2007) identified through their quantitative findings from 24 mothers and 8 fathers that less than a quarter of the sample (7 of 32) felt that their child’s disability had directly affected their family. However, almost half (14 of 32) stated that they felt that their role in caring for the child placed restrictions on everyday family life. The impact of the child’s disability was not one that was all negative. Qualitative findings from Kenny and McGilloway showed that parents had found that their child had brought them joy and fulfilment and described the bond they had as ‘unlike any other’ (2007: 224). Many parents reported that they felt that having a child with an intellectual disability had brought about a positive change in their attitudes and approaches to life and as a result they felt more confident and more empowered (Kenny and McGilloway, 2007). For the most part, parents felt that they supported each other and that their experiences had brought them closer together (Johnson et al., 2006; Towers and Swift, 2006); whilst others felt that other factors were more problematic such as the quality of service provision (Howie-Davies and McKenzie, 2007).

In the wider context of the child’s disability, the impact on families was far reaching in terms of their ability to socialise (Catherall and Iphofen, 2006; Johnson et al., 2006; Todd and Jones, 2005; Towers and Swift, 2006), and findings from Johnson et al. (2006) recognised that mothers felt a sense of worry with regard to problematic behaviours that the child may display in public and felt that this contributed to social isolation. Tiredness and a lack of childcare also contributed to social isolation (Todd and Jones, 2005) as well as the amount of planning and routine that is involved in every activity, meaning that the child’s disability dominated most activities (Johnson et al., 2006; Todd and Jones, 2005). Parents in the study by Catherall and Iphofen (2006) expressed feelings of frustration that the amount of planning and structure that has to go into each activity meant that the family spontaneity was affected. In their report of research into the experiences of fathers, Towers and Swift (2006) identified that fathers found it difficult to find supportive social networks, in part due to working full time as well as taking on the role of carer but also due to a perceived lack of formal support from services and educational establishments. Arguably, parents who experience social isolation are perhaps less likely to access social support leading to further stress.
Service provision and support networks

Another major theme identified within this literature review is service provision and within this are subthemes relating to access to information and parent interactions with support services and professionals and the support needs of parents. Previous studies in this area have shown that delivery of the diagnosis, the levels of support and the information parents receive have a significant impact on the experiences of families (Frey et al., 1989; Hassall et al., 2005; Leino-Kilpi et al., 1993). Using Pearson’s correlation coefficient (University of the West of England, 2007) to analyse data, Howie-Davies and McKenzie (2007) explored the relationship between issues of information, support and stress with 47 parents of children with intellectual disabilities. Results showed that there was a significant relationship between parental stress levels and the number of sources of information that parents accessed and the amount of support that they received from both professionals and support organisations. This relationship identified that the more information and support parents received and the better the quality, the lower their stress levels were with a confidence of $p < 0.05$. However, scores from the short form on the Questionnaire on Resources on Stress (Friedrich et al., 1983) indicated that there was no significant difference to how stress levels were affected by the diagnosis given or to the age at which the child was diagnosed. Howie-Davies and McKenzie (2007) acknowledge that this could be due to the presence of community assessment teams in the area. The overall conclusion from this particular study was that parents were dissatisfied with the lack of information that they received related to their child’s intellectual disability and also with the quality of the information that they received.

Following a pilot study to measure the suitability for use, Kenny and McGilloway (2007) used the Caregiver Strain Questionnaire (Brannan et al., 1997) previously known as the Burden of Care Questionnaire to assess the subjective and objective areas of caregiving strain. Results showed that the participants tended to experience greater difficulty with practical and social care tasks despite managing problem behaviours featuring within the theme of impact upon the family (Johnson et al., 2006). They also expressed a lack of satisfaction with formal support and low service provision.

Johnson et al. (2006) described parents as experiencing a battle for resources and support from professionals and this was further identified by Catherall and Iphofen (2006) who found that parents were left feeling tired and stressed at the amount of energy needed just to access support. For example, the process of assessment, applying for and securing funding and then finding placements and support workers that can meet their needs. This was described by parents as ‘time-wasting’ and ‘unnecessary’ (p. 20) especially as some of the parents who had accessed short breaks and respite for children had felt that the standards of care were not acceptable, leaving them feeling guilty at wanting to take a break from the burden of caring. In a study that looked specifically at the views of fathers, findings indicated that fathers felt that their needs were not considered as their views had not been sought (Towers and Swift, 2006) and that practitioners tended to focus purely on the mother. One possible explanation for this is that the working hours for Children’s Community Services tend to be 9 am–5 pm from Monday to Friday, meaning that the fathers may miss out on visits from professionals and important meetings. Likewise, some fathers felt that they were missing out on their child’s education due to work commitments, whilst one father who had the opportunity to observe his child in school felt that this had helped him to understand his child and to become more patient (Towers and Swift, 2006). This is perhaps reflected by Howie-Davies and McKenzie (2007) as their sample was selected through special schools meaning that potentially some parents were excluded if they worked during school hours.
Perhaps based upon these findings, it would be fair to say that professionals should do more to ensure that parents receive information that is not only relevant to their individual needs but also timely, accessible and of a high quality.

**Transition**

Todd and Jones (2005) carried out in-depth interviews with 30 mothers of children with intellectual disabilities in an area of Wales in order to explore the parallels between the mothers’ midlife transitions (Levinson, 1996) and child transition to adolescence and adulthood. A previous study by Greenberg et al. (1993) recognised that there is a growing body of evidence suggesting that the levels of stress experienced by parents of children with a disability can be directly related to where they are on the ‘life cycle’ (Catherall and Iphofen, 2006: 16). This is a key element in providing high-quality services as recognising transitional events can help professionals to understand the experiences of and support families through transitional periods (Crickmore, 2009). The results of the qualitative study by Todd and Jones (2005) demonstrated that this stage in the mothers’ lives is one that brings with it a strong sense of isolation but also causes them to question their own identity. Some of the mothers reported feeling increasingly different and isolated as their children grew older (Todd and Jones, 2005) in part because they felt that there were fewer opportunities for their child to socialise as a teenager meaning the caring role became more time consuming; this was a concern that was apparent in further qualitative and quantitative studies (Catherall and Iphofen, 2006; Johnson et al., 2006; Kenny and McGilloway, 2007).

Todd and Jones (2005), Johnson et al. (2006) and Kenny and McGilloway (2007) identified that parents were worried about future provision for their children, the changes between children’s and adults services and a perceived lack of services; whilst other parents held expectations that their child would go on to lead ‘normal life patterns’ (Catherall and Iphofen, 2006: 20) and had already began to plan for their child’s future. This is a recurring theme in terms of parents’ hopes and fears; hopes that the children would go on to leave home and perhaps gain some kind of meaningful employment (Catherall and Iphofen, 2006; Johnson et al., 2006) and fears that the child would never leave home (Todd and Jones, 2005). Mothers also spoke of a realisation that their own life plans and expectations had not been achieved yet conflicting emotions meant that there was a sense of fear for the future in terms of the scale of investment in maternal identity and how that may have an impact on a future without their children (Todd and Jones, 2005). Flynn and Russell (2005) and Talbot (2010) spoke about adolescents with intellectual disabilities having an awareness of social barriers and obstacles to suitable education and employment, and Todd and Jones (2005) also found that around this age, young people with intellectual disabilities may develop a greater awareness of their disability. This may prompt parents to develop a greater dependency on formal services; however, limited resources and high demand often lead to conflict with professionals (Todd and Jones, 2003).

Another previous study by Todd (2002) talked about the prospect of death as a hidden concern for parents in terms of the death of the parent and the death of the child. This was mentioned briefly in relation to parental worries about what will happen to the child when parents are no longer around (Catherall and Iphofen, 2006; Johnson et al., 2006; Kenny and McGilloway, 2007). Perhaps one of the most profound findings was illustrated in the study by Catherall and Iphofen (2006) when two fathers shared their private thoughts around taking their child’s life in order to ease the burden on their partner. In fact in some instances these thoughts of taking a child’s life have been carried through, for example, Fiona Pilkington, a woman who took her own life and that of her daughter Francecca Hardwick in 2007 after feeling unsupported following years of harassment towards herself.

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and her daughter who had an intellectual disability (Independent Police Complaints Commission (IPCC), 2011). This is by no means a new phenomenon as demonstrated by the findings of Schultz et al. (1992) and Hornby (1994) around intrusive thoughts of mothers and fathers, respectively.

If professionals are to make the transition process one that is more person-centred and less stressful for families, then perhaps these issues need to be explored further. These findings pose the question of how families would benefit from greater support and information from professionals in relation to transition and future support. The sample sizes in each of the studies in this literature review varied between 14 and 47 participants, and the authors acknowledged that these sample sizes are too small for the results to be generalizable to all parents of children with an intellectual disability. However, the findings do offer some insight into the experiences of the parents who participated in the research.

**Coping**

The final key theme identified was that of parental coping, and many families expressed that the burden of caring was an area that significantly impacted upon their ability to cope (Catherall and Iphofen, 2006; Johnson et al., 2006; Todd and Jones, 2005), with frustration being a common feeling, namely frustration of difficulties in communicating with their child (Towers and Swift, 2006) and frustration of their child’s behaviours especially when routines could not be kept (Catherall and Iphofen, 2006). Another factor that contributed to the parents’ ability to cope was identified as child problem behaviours such as poor concentration, restlessness and mood swings (Kenny and McGilloway, 2007) and disturbed sleep and physical aggression (Johnson et al., 2006). The level of support that parents received also had an influence on their ability to cope (Howie-Davies and McKenzie, 2007; Kenny and McGilloway, 2007), Todd and Jones (2005) and Towers and Swift (2006) found that parents benefitted from the support that they received from each other. However, it is not clear from the literature that was reviewed in this instance how one parent families compare with two parent families in terms of coping and support.

In their mixed method research into how parents cope with their caring role, Kenny and McGilloway (2007) identified several factors that impacted upon the ability to cope in 32 parents. One such factor was the quantity and quality of information given to parents at the time of their child’s diagnosis, with only 13 parents given information at the time of diagnosis and only 3 of them felt satisfied with the information. Of the 32 parents, 19 expressed that they felt they had received insufficient information about their child’s diagnosis as they were growing older. The findings were similar in a qualitative study by Towers and Swift (2006) who interviewed 21 fathers of children with intellectual disabilities in an area of Wales and found that fathers had found it difficult to receive the news of and come to terms with their child’s diagnosis. The fathers described themselves as just ‘getting on with it’ as a way of coping (Towers and Swift, 2006) as did other parents (Johnson et al., 2006; Todd and Jones, 2005). Johnson et al. (2006) talked about this in more detail in relation to the mothers of children with intellectual disabilities and described how some mothers would take a proactive approach to managing their child’s behaviours but if this failed they would take more of a reactive approach managing the problem behaviours. Johnson et al. (2006) felt that this approach perhaps had connotations of learned helplessness theory (Beck, 1976) and ‘hopelessness’ (Padencheri and Russell, 2002), which may be the parents method of avoiding coping. Previous research by Kiernan and Qureshi (1993) identified similar findings and suggested that professionals should take care not to discredit and devalue parents’ approaches to coping.
Some parents spoke about the caring role as one that involves a constant struggle (Catherall and Iphofen, 2006; Johnson et al., 2006; Kenny and McGilloway, 2007; Todd and Jones, 2005; Towers and Swift, 2006), whilst other parents felt the caring role had made them feel more positive in terms of their identity, with findings from Kenny and McGilloway (2007) suggesting that parents became less selfish and judgemental and more confident and optimistic than before their children were born. This perhaps relates to findings by Johnson et al. (2006) and Towers and Swift (2006) who suggested that parents had felt more empowered through supporting their children and felt that ensuring their children’s needs were met was a source of comfort and support.

Conclusion

It is clear that there is a myriad of primary research relating to the experiences of mothers and parents in general caring for a child with an intellectual disability. However, despite the growing body of literature in this area, there is little published research relating to the experiences of fathers caring for a child with an intellectual disability (Gavidia-Payne and Stoneman, 2004; Social Care Institute for Excellence, 2005), and the literature that is available tends to focus purely upon biological fathers that live within the family home (Carpenter and Towers, 2008; Towers and Swift, 2006). Mathieson (2005) highlighted concerns about the quality of support to the parents of children with intellectual disabilities and identified that there was a need for further research into the experiences of fathers as there was currently little research in this area. It has already been acknowledged that fathers play a pivotal role in childcare that is equal to the role of mothers with the introduction of paternity pay in 2003 as a method of encouraging fathers to be more involved in the earlier stages of their children’s lives. Research has shown that fathers too are significantly affected by their role of caring for a child with an intellectual disability, with findings from Catherall and Iphofen (2006) indicating that some fathers had experienced intrusive thoughts relating to the burden they felt was placed on them by caring for a child with a disability. The themes identified within this literature review have shown that parents play an important role in caring for their children but also in supporting their partners.

This literature review has highlighted that parenting a child with an intellectual disability is a role that can lead to family conflict, stress, feelings of exhaustion and resentment and fears for the future. It is also a role that is empowering and offers a degree of fulfilment to some parents (Johnson et al., 2006; Kenny and McGilloway, 2007; Towers and Swift, 2006). This review has also indicated that parents and families have their own strengths, limitations and coping mechanisms, but many feel that they do not receive an adequate level of support and resources from support groups and health care professionals. In terms of increasing parental support, a review of a group-based training intervention programme by Todd et al. (2010) identified that many parents felt that their stress and anxiety significantly impacted upon their ability to manage their child and that their feelings of guilt often meant that they found it difficult to set boundaries for their children. If parents are to feel more in control of how they care for their children and how they cope, then perhaps they may experience reduced stress levels.

Much of the literature reviewed talks about parents finding their partners to be their primary source of support; however, an area that appears to be a gap within the literature relates to contemporary family living, for example, single parent families and stepfamilies. A further area that appears to be neglected is that of the views and experiences of the fathers of children with intellectual disabilities, and the author would suggest that this could be an area for future research. This literature review has demonstrated that some parents experience high levels of stress and uncertainty, especially in relation to their child’s future in terms of both the caring role and the
level of support from services when their child reaches adulthood. This perhaps explains the importance of social networks for parents who are supporting a child with an intellectual disability. These findings emphasise the need for greater collaboration between families and service providers in order to increase the quality of services provided and better support families. Perhaps this could be achieved by offering a family-centred approach instead of a service-centred approach, which can be best achieved by ensuring close liaison between services involved in individual care and a well-planned integrated care pathway.

Research prior to this time period highlighted in this article identified that families of children with intellectual disabilities were disadvantaged financially, socially and in terms of housing and employment as well had the detrimental effects on their marital relationships (Beresford, 1995; Walker and Walker, 1998). The current literature highlights that is still the case and is one that still requires further exploration. The Department of Health (2001) publication ‘Family Matters: Counting families In’ identified transition as an area that was difficult to manage however it was one that played a key role in reducing stress and anxiety for families. As a result, a recommendation was made that services take more of a long-term view of transition planning for individuals with intellectual disabilities. Although there are more services and initiatives available for transition, there is such high demand that many families may be unable to access these services hence the need for further funding for transitional services.

It should be noted that not all parental carers wish to join or are able to join carers’ groups and such, so there is likely to be a hidden population whose views may differ from those who are recruited for research through their participation in groups or services.

**Appendix 1. List of articles subjected to literature review**

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Published</th>
<th>Approach: Methods</th>
<th>Main theme</th>
</tr>
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<tbody>
<tr>
<td>Catherall and Iphofen (2006)</td>
<td>Learning Disability Practice</td>
<td>Qualitative: Focused, unstructured and semi-structured interviews using a phenomenological approach</td>
<td>Parental experiences; children with severe intellectual disability</td>
</tr>
<tr>
<td>Howie-Davies and McKenzie (2007)</td>
<td>Learning Disability Practice</td>
<td>Quantitative: Postal questionnaires and rating scales</td>
<td>Diagnosis, stress and information; parental coping</td>
</tr>
<tr>
<td>Johnson et al. (2006)</td>
<td>Journal of Child Health Care</td>
<td>Qualitative: Semi-structured interviews and grounded theory methods</td>
<td>Problem behaviours; maternal perspectives</td>
</tr>
<tr>
<td>Todd and Jones (2005)</td>
<td>Journal of Intellectual Disability Research</td>
<td>Qualitative: In-depth interviews</td>
<td>Maternal attitudes and maternal transition</td>
</tr>
</tbody>
</table>
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