



Review article

What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? A qualitative meta-synthesis

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ABSTRACT

The aim of the meta-synthesis was to determine any difficulties experienced by caregivers relating to the sexuality of people with intellectual disabilities and how they address those difficulties. A qualitative meta-synthesis was used to integrate the findings from 17 papers about these topics. The synthesis produced five concepts: 'Fear and Uncertainty', 'Impact of Perceptions of Sexuality', 'The Same and Different', 'Balancing the Roles of Protector and Facilitator' and 'Conditional Sexuality: Conditional Support'. The findings suggest key issues for caregivers in relation to addressing the sexual needs of people with intellectual disabilities and highlight the possible implications of caregivers own views on their practice. These issues are discussed and in conclusion the review offers explanations about what the difficulties for caregivers are and how they might be addressed, as well as recommendations for future research.

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1. Introduction

The principles of rights, independence, choice and inclusion have been on the political agenda for people with intellectual disabilities since the introduction of normalisation principles 40 years ago (Wolfensburger, 1972). Within the UK, policy such as 'Valuing People' (DoH, 2001) puts these concepts at the foundation of service provision for people with intellectual disabilities. There has been some debate in the literature about translating these principles into practice in a meaningful way (Beamer & Brookes, 2001; Edge, 2001; Harris, 2003; Jenkinson, 1993; Kinsella, 2000; Thompson, 2003).

Putting policy into practice has implications for people with intellectual disabilities, and for their caregivers. Difficult decisions, moral pressures and judgements arise from attempting to implement these principles (Clegg, Murphy, Almack, & Harvey, 2008). For example, parents report social inclusion to be desirable for their child and that morally they should try to enable the child to achieve social inclusion (e.g., in attending mainstream school). However, achieving this is often not possible for their child, which has resulted in parents 'feeling negatively judged by peers and professionals' (Clegg et al., 2008, p. 92). Consequently, attempts to integrate people with intellectual disabilities into 'mainstream' communities have seen varied levels of success, with negative aspects including reduced quality of life for informal caregivers (Cummins, 2001) and increased likelihood for negative social experiences for people with intellectual disabilities (Cummins & Lau, 2003).

The introduction of person-centred planning and direct payments were supposed to enable people with intellectual disabilities to have more choices (Concannon, 2006). However, concerns remain about when caregivers should direct people with intellectual disabilities in making a different choice, and when this begins to infringe upon the right to free choice (Smyth & Bell, 2006). These issues can leave caregivers in a difficult position when faced with situations where rights, independence, choice and inclusion may be important.

When considering relationships, the importance of rights is further emphasised within the *Human Rights Act (1998)*, particularly regarding respect for private and family life (article 8) and the right to marry (article 12).

In a review of the literature on sexuality, relationships and sexual needs, McGuire and Bayley (2011) found the continued existence of restrictive practices and barriers to sexual expression, despite attempts to change this at a policy and service level. Within the review, the ability of people with intellectual disabilities to make decisions about sexual matters was described as a 'fluid process' (McGuire & Bayley, 2011, p. 399) whereby the capacity of an individual to consent to a sexual relationship could change over time. They identified a need for further research into caregiver experiences of issues relating to sexuality and relationships when supporting people with intellectual disabilities.

In light of this recent recommendation, it is timely to determine what is already known about caregiver experiences of supporting people with intellectual disabilities with their sexual needs. Quantitative research in this area (Cuskelly & Bryde, 2004; Grieve & McLaren, 2008; McCabe, 1999) identifies factors that may influence caregiver attitudes towards relationships for people with intellectual disabilities (age, formal or informal caregiver, community or residential setting). This research is limited because it does not give an in depth account of caregiver experiences. It is difficult to ascertain what could be done to change things practically because the research does not explore the reasons behind the attitudes that caregivers report. In contrast, qualitative research captures in depth the whole range of the experience of the phenomenon it sets out to investigate, and the meaning of that phenomenon for participants (Patton, 2002). Therefore, it is possible to understand the experience that caregivers have, and consequently how those experiences might be changed.

Despite the value of qualitative research, until relatively recently there was not a recognised analogous method to the quantitative systematic review for synthesising findings from multiple qualitative studies. The development of meta-synthesis has emerged as the principle approach to achieving this (Noblit & Hare, 1988). Therefore the decision was made to conduct a qualitative meta-synthesis to explore how caregivers managed these complex issues by asking what are the difficulties experienced by caregivers relating to the sexuality of people with intellectual disabilities and how they address these difficulties?

The present review is a systematic synthesis of empirical qualitative literature relating to the difficulties caregivers face in relation to sexual interest in people with intellectual disabilities and how they address these difficulties. This review is needed because there have been no reviews of the qualitative literature within this area and a review will allow readers to gain an overview of the understandings of this area so far, illuminate possible directions for future research and hopefully have a positive impact upon social policy and practice, improving the experiences of people with intellectual disabilities.

2. Method

2.1. Research questions

The review aimed to identify what caregivers' experiences and perceptions regarding sexual needs of people with intellectual disabilities are. The main research question asks what are the difficulties experienced by caregivers relating to the sexuality of people with intellectual disabilities and how do they address them? These questions will hopefully illuminate examples of good practice and possible barriers to achieving good practice, as well as suggestions for improving services.

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