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"In our house we're not terribly sexual": Exploring the Barriers to Supporting Intellectually Disabled People in the Area of Sexuality and Intimacy

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Abstract

How support workers enable, regulate or constrain the sexual expression of intellectually disabled people who live in service agency group homes is the subject of this thesis. A general literature search of what intellectually disabled people currently experience in their lives, including their experiences in the area of sexuality and intimacy, begins this investigation. Secondly, an extensive literature review of the support role, incorporating an appraisal of past and current issues related to the support position in general and to the area of sexuality support in particular, was completed. What intellectually disabled people themselves would like in relation to sexuality and intimacy support was included in this section. Thirdly, a review of research studies focussing on the operation of the support position within service agency systems was undertaken.

These explorations revealed a high degree of reluctance on the part of workers to provide assistance in the sexuality area, despite a proven necessity for support to be made available to the intellectually disabled people they worked with. Review research studies suggested a variety of causal factors in explanation of this reluctance. These suggestions link to two meta-reason positions. Failure to prove support either stemmed from individual worker's inactions due to ignorance and/or incompetence, or from wider systemic failures on the part of agency services to positively value and support this key service role in this area. However, little if any analysis of the possible influence of the broader social, emotional and cultural contexts, in which the concepts 'sexuality' and '(intellectual) disability' are located, could be found in the studies reviewed.

Eleven in-depth interviews were conducted with front-line support workers about their sexuality support practice. Preliminary readings of the interview texts revealed a similar reluctance on the part of the workers concerned to assist those they worked with in this area. Interview texts were then subjected to a post-modernist inspired, interpretive discursive analysis. This analysis uncovered and tracked how key power/knowledge effects inherent in the terms '(intellectual) disability', 'sexuality',

‘gender’ and ‘desire’ inhering in the concept of an ‘ideal (sexual) couple’ interweave to shape the ‘no support necessary’ practice responses held in worker’s interview talk.

From this exploration it is suggested that research studies of workers’ practices as an aspect of the promotion of change in support outcomes in the sexuality support area need to go beyond the parameters of recommendations that stem from considerations of either individual or systemic limitation alone. It remains a convincing point to suggest that poorly performing workers need retraining in this area and the overall value of the support role within service organizations needs reshaping. However, future research recommendations also need to engage more directly and effectively with the effects of the wider social and emotional “ideal (sexual) couple” ambiguities that also influence worker’s lack of assistance in this complex and sensitive support area. The use of a post-modern perspective as a helpful conceptual tool in unpacking the power these ambiguities hold within the support position is offered as a productive way forward for future research and practice development.

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Carol Hamilton
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