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Review article

Providing services in the United Kingdom to people with an intellectual disability who present behaviour which challenges: A review of the literature

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ABSTRACT

There is ongoing debate about the best model of service provision for people with an intellectual disability who present severe behavioural challenges. The present paper reviewed research which evaluated a range of UK service provision in terms of impact on challenging behaviour and other quality of life indices. A literature search was carried out for English language papers from 1990 to 2010 using a range of databases. Secondary searches were carried out from references of relevant papers. Very few evaluations were found. The available research indicates that, on the whole, specialist congregate services for individuals with challenging behaviour appear to use more restrictive approaches which have limited effect on reducing challenging behaviour. The evidence for peripatetic teams is somewhat unclear. The two studies reviewed showed positive outcomes, but both had limitations that made it difficult to generalize the results. A similar limitation was found with the sole evaluation of a community based service. It is unlikely that one model of service provision will meet the needs of all individuals, however, more robust evaluations are required of existing service models to allow commissioners, service users, their families and carers to make fully informed choices about effective services for those who challenge.

Contents

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1. Introduction

The UK policy of closing large scale institutions for people with an intellectual disability over the past 3 decades (NHS and Community Care Act, 1990) has been accompanied by an ongoing debate about the best form of service provision for people with intellectual disability who present severe behavioural challenges (Mackenzie-Davies & Mansell, 2007). It is estimated that between 5% and 15% of people with an intellectual disability will present with behaviour that is perceived to be challenging (Ball, Bush, & Emerson, 2004) and that it is likely to persist over time (Totsika, Toogood, Hastings, & Lewis, 2008). Such behaviour has a range of associated negative outcomes, including risk to the client and others, increased staff stress and anxiety (Emerson et al., 2000), increased risk of placement breakdown (Broadhurst & Mansell, 2007) and resource implications, with services for those with more severe intellectual disability and severe challenging behaviour costing more (Knapp, Comas-Herrera, Astin, Beecham, & Pendaries, 2005).

Challenging behaviour is also associated with the use of restrictive practices such as physical and chemical restraint (Emerson et al., 2000; Sturmey, 2009). Anti-psychotic medication is used widely as an intervention for challenging behaviour (McGillivray & McCabe, 2005), despite a lack of evidence that it is a cost effective approach (Romeo, Knapp, Tyrer, Crawford, & Oliver-Africano, 2009) or that it reduces challenging behaviour in those who don't have an associated mental health problem (Bhaumik et al., 2009; Brylewski & Duggan, 2004; Tyrer et al., 2008).

Models of service provision for those who present with behaviour that challenges tend to fall into three main categories: specialist in-patient units; community provision by local services and community provision by specialist peripatetic teams (Xenitidis, Henry, Russell, Ward, & Murphy, 1999). These different models are perceived as having their own advantages and disadvantages (Mackenzie-Davies & Mansell, 2007; Newman & Emerson, 1991).

1.1. In-patient units

In-patient units are usually staffed by multi-professional teams and specialize in the assessment and treatment of those who provide more extreme challenges. Early on researchers outlined both the potential benefits and drawbacks associated with this form of service provision. In terms of the former, it was seen as providing a solution to community placement breakdown and other acute situations, offering expert support for those with more severe or specialist needs and providing expertise to community staff (Brigend & Todd, 1990; McBrien, 1987; Newman & Emerson, 1991; Royal College of Psychiatrists, 1986).

A number of disadvantages to specialist residential care have also been identified, including undermining the ability of community staff to develop the skills required to deal with more complex challenging behaviour, bed-blocking due to a lack of suitable community resources and challenging behaviour being exacerbated by the fact that residents have mixed needs (Blunden & Allen, 1987; Newman & Emerson, 1991), particularly as there is limited evidence for the benefits of locating people with challenging behaviour together (Grey & Hastings, 2005). It is also argued that service coordination, liaison with local services and maintaining social relationships are all more difficult for those who are placed in services out with their local area (Mackenzie-Davies & Mansell, 2007). Mackenzie-Davis and Mansell summarise the early research in this area and conclude that while there is evidence that specialist in-patient units do provide assessment expertise and effective short-term interventions, there are difficulties generalising these interventions beyond the in-patient settings. Similarly, Allen, Lowe, Moore, and Brophy (2006) conclude from a Welsh survey of out of area placements, that despite being characteristically expensive, they show limited evidence of providing a higher quality of service.

1.2. Specialist peripatetic support teams

Specialist peripatetic support teams are designed to provide proactive work and intensive support to individuals and their carers within their existing home. Most are provided via the NHS and adopt a behavioural approach (Emerson, 1996). Input can be of varied duration and can range from consultation and training to intensive behavioural support (Emerson, 1996; Toogood, 2000). Early research suggested that the most effective teams used interventions that were underpinned by and derived from an applied behavioural approach to challenging behaviour (Lowe, Felce, & Blackman, 1996). Additional requirements identified for successful intervention were commitment from and communication with local intellectual disability services, the need for the specialist service to provide 'on the job' training, modelling and feedback for support staff, the need for strong team-work, staff consistency, client focussed meetings and staff supervision, well-defined and shared goals and evidence based practice (Mansell, McGill, & Emerson, 2001; Toogood, 2000).

Research by Emerson (1996) noted that, while the majority of the teams surveyed in England and Wales felt their interventions for challenging behaviour were effective, closer inspection indicated that most cases which were closed on the basis of 'success' were due to factors other than improving challenging behaviour. In addition, many teams expressed