



Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making

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ABSTRACT

There is limited literature on the processes of choice-making in families of young people with learning disabilities. This paper examines the factors considered by parents of young people with learning disabilities when deciding their own and their child's role in a range of significant choices (health, social care and education) about their child's life. The paper reports data collected from a sub-sample of 14 parents recruited from 11 families participating in a longitudinal (2007–2010) qualitative study based in England. The parents all had children with learning disabilities and participated throughout the study. Data were collected over three semi-structured interviews. Parents' accounts demonstrated a continuum of parental involvement ranging from young people being unaware a choice was taking place to young people being fully involved in choice-making. Parents did not always adopt the same approach to choice-making; different approaches to their own and their son/daughter's level of involvement emerged when parents discussed different choices. Five choice-making factors are presented. These factors were used by parents to guide their own and their child's level of involvement. Although young people's level of understanding was considered, it was not always the most important factor. Other factors were important and, at times, could be considered more important by parents. The other factors were: parents' views on the nature of the choice, protecting their child, parents' personal attitudes/beliefs and confidence in practitioner knowledge. Insights from these factors highlight some important practice issues when practitioners work with families of young people with learning disabilities making significant life-choices.

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1. Introduction

Encouraging service users, including people with learning disabilities and their families, to make choices and take greater control of their lives is a key English health and social care policy and practice objective (Department of Health, 2006, 2009; HM Government, 2007). For people with learning disabilities, there are many well-rehearsed debates surrounding the importance of choice, for example, from the early ideas of normalisation theory (Wolfensberger, 1972) to broader social and psychological self-determination theories (such as, Willink, Widdershoven, van Schrojenstein Lantman-de Valk, Metsemakers, & Dinant, 2009). Increasing disabled people's choice and control is also an important part of the social model of disability (see for example Abberley, 1987; Barnes & Mercer, 2010; Oliver, 1996) and is advocated by disabled people themselves. This has been recognised in English policy by such strategies as Valuing People (Department of Health, 2001, 2009) and the movement towards person centred planning (HM Government, 2007). Choice and choice-making opportunities are also important for young people with learning disabilities

approaching adulthood as choice-making is viewed in wider society as part of the transition to adulthood (Department of Health, 2008a).

However, there is a limited literature on the processes of choice-making in families of young people with learning disabilities. The aim of this paper is to explore the choice-making considerations that parents of young people with learning disabilities take into account regarding their own and the role of their child when faced with significant choices regarding their son/daughter's life. The paper demonstrates that parents do not always adopt the same choice-making role; different types of choices lead parents to adopt different choice-making roles. Increasing practitioner awareness of these factors can help to facilitate more sensitive and flexible working with families of young people during choice-making.

2. Choice-making and people with learning disabilities

Historically, it was believed that people with learning disabilities could not make choices, nor would it be wise to allow them to do so since their lack of understanding and vulnerability could lead them to make 'wrong' or 'risky' decisions (Guess, Benson, & Siegel-Causey, 2008; Jenkinson, 1993; Kearney & McKnight, 1997; Smyth & Bell, 2006; Ware, 2004).

In recent years, this assumption has been challenged by people with learning disabilities themselves and is supported internationally

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by the findings of research (for example, Cannella, O'Reilly, & Lancioni, 2005; Lancioni, O'Reilly, & Emerson, 1996). It has demonstrated that people with learning disabilities (even severe) can make choices, but that this ability is moderated by the type of choice being made and the support available to them. Authors have also moved away from a simplistic notion of involvement. Involvement in choice-making is now regarded as operating on a continuum (Cannella et al., 2005; Lancioni et al., 1996; Smyth & Bell, 2006). Furthermore, in England, legally people with learning disabilities' understanding and 'capacity' should be presumed until otherwise established (England and Wales, Mental Capacity Act, 2005).

An important distinction needs to be made between 'expressing a preference' and 'making a choice'. Preferences are presented as expressing a subjective like/dislike of a particular thing which the individual already has some prior experience (for example, preferred foods, activities, people). In contrast, choice-making is a process in which options or alternatives are identified, weighed up and a selection made (Kearney & McKnight, 1997; Smyth & Bell, 2006; Ware, 2004). Choice-making is therefore a cognitively more complex and demanding activity. At the same time, choices vary from simple to complex according to the demand made on an individual's cognitive processing skills and abilities. For example, making choices about the future requires the ability to anticipate events and weigh-up potential consequences (Ware, 2004).

International research on the barriers to choice-making by people with learning disabilities has typically focused on barriers in service settings, such as organisational structures and staff practices, beliefs and attitudes (Cannella et al., 2005; Harris, 2003; Jenkinson, 1993). Similarly, research with young people with learning disabilities has also focused on formal contexts (schools, community living), for example, the literature on self-determination (Chambers et al., 2007). Much less is known and understood about choice-making within families. For example, in programmes to teach people with learning disabilities choice-making skills, few explore in-depth the important role and attitudes of parents (Chambers et al., 2007; Henderson, 1994; Small, Pawson, & Raghavan, 2008).

3. Choice-making in families

However, there is a growing general international literature on the different roles family members play in choice- or decision-making; for example, in health or treatment related choices. This has demonstrated the role played by parental attitudes and beliefs, and parenting styles in determining children's involvement in choice-making (Commendador, 2010; Coyne, 2008; Jackson, Cheater, & Reid, 2008; Lease & Dahlbeck, 2009; Mack et al., 2011; Peterson-Badali, Morine, Ruck, & Slonim, 2004; Pyke-Grimm, Stewart, Kelly, & Degner, 2006).

The limited research on families of young people with learning disabilities recognises that practitioners can play an important role in family choice-making. This is demonstrated in the recent conversation analysis based research of Pilnick, Clegg, Murphy, and Almack (2011, 2010) documenting the importance of practitioners' subjective understandings of young people with learning disabilities and their parents' choice-making interactions. How professionals interpret and act on these family interactions can guide service outcomes for both young people and their parents.

Research involving families of young people with learning disabilities has also identified that parents can facilitate or impede their son/daughter's involvement in choice-making (Almack, Clegg, & Murphy, 2009; Grigal, Neubert, Sherril Moon, & Graham, 2003). However, less is understood about the specific roles parents may assume when there are choices to be made for/about their son or daughter, and the processes by which they decide about the role the young person will play in the choice-making process (Bianco, Garrison-Wade, Tobin, & Lehmann, 2009; Murphy, Clegg, & Almack, 2011; Rueda, Monzo, Shapiro, Gomez, & Blancher, 2005).

Two generic USA based studies offer models of the roles parents may assume and how, in consequence, this influences their child's involvement in choice-making (Lindstrom, Doren, Metheny, Johnson, & Zane, 2007; Snethen, Broome, Knaf, Deatrck, & Angst, 2006). Snethen et al.'s (2006) study on decision-making around chronically ill children's participation in clinical trials identified four roles parents assumed as this choice was being made: 'exclusionary', 'informative', 'collaborative' and 'delegated' roles. 'Exclusionary parents' aimed to protect their child and this frequently resulted in their son/daughter not being involved in the choice being considered. 'Informative parents' aimed to help their child understand and participate in choice-making but wanted to make the final decision. 'Collaborative parents' sought to support and empower their child's choice-making and 'delegatory parents' largely handed over choice-making responsibility to their child.

Lindstrom et al.'s (2007) study looked at parents' attitudes to their child's (all of whom had 'special educational needs') involvement in choosing their post-school destination. They present a continuum of parental involvement based on three roles: 'protectors', 'advocates' and 'removed'. These are broadly similar to the roles identified by Snethen et al., with Lindstrom et al.'s 'advocating' parents straddling Snethen et al.'s 'informative' and 'collaborative' roles.

To begin addressing gaps in the literature, this paper reports a study which, in part looked at parental perspectives on their and their child's role in choice-making when there were significant choices to be made regarding their son/daughter's life. All the young people in this sample had learning disabilities. Separate papers report the young people's perspectives (Mitchell, 2010a,b, forthcoming).

4. Method

4.1. Study design

The findings reported here are drawn from an English longitudinal qualitative based study (the 'Choice and Change' project) of the choices made by three groups of disabled people (adults, older people and young people with life-limiting conditions and their parents) regarding their health, education and social care over a 30 month period. Data were collected during three semi-structured interviews conducted between 2007 and 2010. Ethical approval was received from an English National Health Service medical research ethics committee.

4.2. Selection and recruitment

The sample of young people and their parents were recruited from two English children's hospices. Hospices were chosen as an efficient route to recruit young people with degenerative conditions, as they provide support for a wide range of degenerative conditions and assist young people and their families at different stages of degeneration, from initial diagnosis to end of life care. The young people in this study were at different stages of their illness trajectory; however, the research did not involve young people in the end stages of life. Before seeking to recruit young people to the study, the researcher consulted hospice staff about each young person's stage of degeneration.

Hospice managers distributed project information to families with young people aged 13–21 years. Families contacted the researcher if they were interested in participating. Thirty-three families were recruited to the study. Recruitment proved challenging, reasons for non-response were not collected but hospice staff indicated that young people's deteriorating health had affected recruitment.

This paper focuses on findings from a sub-sample of 14 parents representing 11 families. This sub-sample met two criteria: i) their child had learning disabilities; ii) they had participated in all three-interview rounds. Participation in all three interviews was important as it provided data on different choices and opportunities for reflection. Table 1 documents key characteristics of this sub-sample and the choices parents chose to discuss during the interviews.

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