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Health and wellbeing during transition to adulthood for young people with intellectual disabilities: A qualitative study



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ABSTRACT

Background: Transition to adulthood may have negative consequences for health and wellbeing in individuals with intellectual disabilities (ID), but this aspect of transition has received little investigation. This qualitative study aimed to explore the transition experiences of individuals with ID from their own perspectives, and from that of their parents, in order to identify health or wellbeing implications of transition.

Method: Semi-structured interviews were conducted with 17 young people with mild, moderate and severe ID aged 16–27 years and with 23 parents of young people with mild, moderate, severe and profound ID aged 16–26 years. Interviews were analysed using thematic analysis, deploying both emic and etic coding categories.

Results: This study provides direct insights into the issues on health and wellbeing that young people with ID and their parents find important during transition. The primary health implication of transition centred on mental health and wellbeing; young people experienced heightened anxiety during transition, and themes identified as contributing to anxiety included: a lack of meaningful activity following school exit; inadequate support during transition; and difficulties associated with 'growing up'. Problem behaviours and obesity were also implicated.

Conclusion: The transition from school needs to be better supported in order to ease anxiety for young people during this difficult period.

What this paper adds?

Transition is recognised in academic literature and governmental policy as a difficult period for the population with ID. Despite this recognition, there has been little study of health and wellbeing outcomes for young people with ID during transition. This paper employs the perspectives of both young people with ID and their parents to document the ways in which transition to adulthood affects health and wellbeing, demonstrating that school exit and the transition to adult life have negative consequences for mental health and wellbeing in this population. Perspectives were taken from participants at various stages of the transition, facilitating the elucidation of the effects of this period across the whole spectrum of transition to adulthood. Furthermore, this paper is novel in its inclusion in interviews of individuals with severe ID.

1. Introduction

Transition refers to the movement from school to adulthood; in the population with ID, transition also involves moving from child

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to adult health and social services. Transition may be a challenging time for young people with ID, since it involves a considerable change in daily routines and available service provision. Traditionally, transition involves leaving school and entering the workplace and developing independence from parents; more recently young people may spend more prolonged periods of time in further education, with continued dependence on parents (Arnett, 2000). Nevertheless, young people with ID may not achieve many typical goals of adulthood that their non-disabled contemporaries go on to achieve. The literature demonstrates low employment figures for young adults with ID (e.g. Scottish Learning Disabilities Observatory, 2016; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009; Grigal, Hart, & Migliore, 2011), as well as low levels of community participation (e.g. Verdonschot et al., 2009; Small, Raghavan, & Pawson, 2013) and continued residence in the parental home well into the 30s (Gray et al., 2014). Young people with ID may hence be prevented from assuming 'adult' roles, thus delaying some aspects of transition to adulthood (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006).

Less is known about health (both physical and mental) and wellbeing outcomes during transition in this population. Wellbeing is defined in the Oxford English Dictionary as: "the state of being comfortable, healthy and happy", involving general life satisfaction and a feeling of fulfilment (Shah & Marks, 2004). Health in children and young people with ID is poor compared to the typically developing population. Those with ID are more likely to have mental health disorders (Rutter, Tizard, & Whitmore, 1970; Linna et al., 1999; Dekker, Koot, Ende & Verhulst, 2002; Emerson & Hatton, 2007a; Emerson & Einfeld, 2010) than their typically developing peers. They are also more likely to be rated as having poor general health by their parents (Emerson & Hatton, 2007b) and to have physical health conditions, including epilepsy (Forsgren, Edvinsson, Hans, Heijbel, & Sidenvall, 1990; Steffenburg, Hagberg, Viggedal, & Kyllerman, 1995; Airaksinen et al., 2000), sensory impairments (Van Schrojenstein Lantmen-de Vaulk et al., 1997; Nielsen, Skov, & Jensen, 2007), and gastro-intestinal disorders (Van Schrojenstein Lantmen-de Vaulk et al., 1997).

A systematic review conducted by Foley, Dyke, Girdler, Bourke, & Leonard, (2012) highlighted the importance of environmental factors during transition in the population with ID. A lack of daytime activity may negatively affect mental health outcomes and result in a loss of functional skills (Gauthier-Boudreault, Gallagher, & Couture, 2017). Additionally, disruptions in service provision may have negative consequences for the management of physical health conditions. Transition may also have a negative effect on parents of young people with ID (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2017), with potentially transactional, reciprocal and spiralling health and wellbeing interactions for both the young person and the parents.

Transition may be especially problematic given that the support received during this period is often described by families as inadequate (Todd & Jones, 2003; Hudson, 2006; Hetherington et al., 2010; Murphy, Clegg, & Almack, 2011; Gauthier-Boudreault et al., 2017). Qualitative studies demonstrate that transition planning, which aims to map out daily activities and supports beyond school, may be poor, failing to take account of a young person's individual needs and aspirations (Beresford, 2004). Guidelines recommend that transition planning begin when a young person is between the ages of 14 and 16 years, but qualitative studies suggest that current transition planning practices probably occur too late in a young person's school career to be effective (e.g. Hetherington et al., 2010). Furthermore, transition from child to adult services may be discontinuous and chaotic, with differences in style of care provision contributing to difficult moves (Hudson, 2006). It is possible that a combination of these factors may contribute to negative implications for these young people's overall wellbeing.

A systematic review of the literature on transition and health and wellbeing outcomes in young people with ID found only 17 relevant articles (Young-Southward, Philo, & Cooper, 2016). While the articles reviewed suggested the presence of some health and wellbeing issues during transition, including ones to do with sexual health, interpersonal conflict and obesity, no studies specifically examined the ways in which transition to adulthood affects young people's general health and wellbeing, including mental health. This gap in the literature is concerning given the substantial changes in life circumstances that transition from school precipitates, as well as the negative vocational and social outcomes reported in the literature that may have both direct and indirect implications for health and wellbeing. Furthermore, data from young people with ID themselves on this topic, as well as data relating to the ways in which transition impacts health and wellbeing in different ways across the ID continuum, is lacking (Young-Southward et al., 2016).

This study therefore sought to describe how transition from school to adulthood affects the health and wellbeing of individuals with ID from the perspectives of young people with ID and those of their parents. As suggested earlier, the process of transitioning to adulthood may take longer in the population with intellectual disabilities than in the typically developing population, perhaps spanning into the 20s. Henceforth, the term 'young people' will be used to describe individuals experiencing this transition period.

2. Methods

2.1. Study design

The study has a hermeneutic qualitative design (Guba & Lincoln, 1994), whereby young people and their families disclosed their own narratives of transition, and the researcher subjectively appraised the claims made by interviewees. In this way, the interviewees' and researchers' frames of meaning were brought into dialogue in order to produce a plausible interpretation of the issues associated with transition. While it was felt important to include the voices of young people with ID in the research, it was also acknowledged that parents could offer important insights into the transition experience of their children, especially in cases where young people would be unable to take part in an interview due to communication impairments.

2.2. Recruitment

Approval for the study was granted from the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics

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