



Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing?



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ABSTRACT

Introduction: At the age of 21, the trajectory of services offered to youth with profound intellectual disability (ID) change significantly since access to specialised services is more limited. Despite the desire of parents to avoid any impact on their child, several factors can influence the course of this transition. However, there is little research on facilitators and obstacles to the transition to adulthood, and impacts on people with a profound ID. It is therefore difficult to provide solutions that meet their specific needs.

Objective: The study aimed to document the needs of parents and young adults with profound ID during and after the transition to adulthood by exploring their transitioning experience and factors that influenced it.

Method: Using a descriptive qualitative design, two individual semi-structured interviews were conducted with fourteen (14) parents of young adults aged between 18 and 26 with a profound ID.

Results: At this point, many material, informative, cognitive and emotional needs of young adults and their parents are not met. Obstacles, mainly organisational, persist and result in a particularly difficult transition to adulthood experience.

Conclusion: By knowing the specific needs of these families, it is possible to develop and implement solutions tailored to their reality.

What the papers adds?: The transition to adulthood is a critical period for families with young adults with an intellectual disability (ID), a reality observed internationally. Current literature on all levels of ID suggests some barriers to transition that lead to negative impacts on both parents and young adults with ID. However, presently, very little research exists on the reality of families of young adults with profound ID and factors influencing transition to adult life. Most of studies target people with mild to moderate ID. Considering the significant disabilities of people with profound ID, it is possible to imagine that their experience of transition will be even more difficult and they will present specific needs. The lack of understanding of these needs makes it difficult to introduce solutions tailored to their reality. The results of this current study suggest that many needs of young adults with profound ID and their parents are not met despite existent transition planning services. Transition to adulthood seems particularly difficult for these families who face many challenges. Parents in this study proposed different obstacles during

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transition to adulthood that could be improved for creation of future solutions adapted to their reality.

1. Introduction

Intellectual disability (ID) is a neurodevelopmental disorder characterised by intellectual and adaptive behavior deficits (American Psychiatric Association [APA], 2013; Katz & Lazcano-Ponce, 2008; Schalock et al., 2010). On a continuum of abilities and skills, there are four levels of ID, i.e. mild, moderate, severe and profound (APA, 2013; Arvio & Sillanpää, 2003). Profound ID is the most severe level and represents about 6 in 10,000 people (Arvio & Sillanpää, 2003). People with profound ID present significant language incapability and around 82% have behavioural difficulties, such as self-mutilation, striking and banging head (Poppes, Van Der Putten, & Vlaskamp, 2010). However, major disabilities are related to intellectual functioning, which significantly limit the person in all her life habits (APA, 2013).

In Quebec (Canada), before 21 years of age, children and youth have the opportunity to attend a public specialised school where a significant effort is made to improve their abilities and capabilities using motor, sensory, cognitive and social stimulation. During this period, specialised school works in collaboration with paediatric health and rehabilitation centre to offer rapid and adapted services tailored to their needs. However, at the age of 21, young adults with profound ID must leave specialised public school because of the termination of public funding for their attendance and transfer from paediatric health and rehabilitation services to adult services (Government of Quebec, Act to secure the handicapped in the exercise of their rights, 2015, *Gouvernement du Québec*, 2015). For most parents, these events are anticipated long before their children reach the fateful age. This awareness about the upcoming school-leaving age and transfer in health services places families of young adults with profound ID in a transition state, which will end once they find a new stable and secure reality (Kralik, Visentin, & Van Loon, 2006). In this study, transition is defined as a dynamic process that results of a complex interaction between the person and her environment that takes place during a period of movement from one state of certainty to another, with an interval of uncertainty and changes between the two (Chick & Meleis, 1986; Golan, 1981).

This transition process to build a new reality may not be experienced in the same way by people, even if the circumstances are similar. Indeed, the sequence of three distinct phases of the transition, including the end of one reality, the beginning of a new one and an important gap between the two (Bridges, 2004), does not differ between people, but the duration of each phase and the level of distress experienced by the affected person vary (Chick & Meleis, 1986). It is well known that transition phase is very stressful for parents of youth with ID and may cause significant effects on the whole family (Blacher, 2001; Davies & Beamish, 2001; Davies, Rennick, & Majnemer, 2011; Rapanaro, Bartu, & Lee, 2008). However, in the literature, few studies addressed specifically what families of young adults with profound ID are experiencing. Considering the significance of these young adults' disabilities and the lack of options offered to fill the void after leaving school, these families might go through an even more difficult experience. In addition, the experiences of these families might be all the more difficult, knowing the impact of leaving school on the young adult and his family. Indeed, when people with ID attend public specialised school, the main objective is to maximize their abilities. However, after the end of school, studies on ID, at all levels, suggest a loss of abilities acquired during school (Bernard & Goupil, 2012; *Office des personnes handicapées du Québec*, 2003). Leaving school could also affect young adults with ID by causing or worsening behavioural and psychiatric problems (Blacher, 2001; Rapanaro et al., 2008; Taylor & Seltzer, 2010). The transition to adulthood may also cause inconvenience to parents. It is characterised by anxiety and frustration in their lives due to having to seek new services, a lack of support, an increased financial need, often unmet, and the loss of their social network (Bernard & Goupil, 2012; Davies et al., 2011; Rapanaro et al., 2008). Parents are also confronted to the necessity of reducing or stopping to work since they must now take care of their child who used to attend school on weekdays (Barron, Molosankwe, Romeo, & Hassiotis, 2013; Davies & Beamish, 2009; Foley, Dyke, Girdler, Bourke, & Leonard, 2012).

In their scoping review, (reference had been removed to allow anonymity) have stated that most of the literature were related to mild to moderate ID and were targeting concepts that were not applicable for profound ID during transition to adulthood, like employment and postsecondary education. In fact, current studies mentioned the limited post-school activities for young adults with pervasive supports needs and the lack of meaningfulness of these opportunities (Carter, Austin, & Trainor, 2012; Davies & Beamish, 2001; Gray et al., 2014; McCausland et al., 2010; Rossetti, Lehr, Lederer, Pelerin, & Huang, 2015), but it is still difficult to understand the reality of people with profound ID since most of articles combine participants presenting different types or levels of disabilities. Literature on ID generally agrees that obstacles persist with regards to supporting parents in preparing the transition to adulthood. Indeed, there are three main challenges in the literature (Davies et al., 2011; Foley et al., 2012; Hubert, 2010; Hudson, 2003; Shogren & Plotner, 2012; Ward, Maliett, Heslop, & Simons, 2003). We talk about a discontinuity of educational and health services provided during and after the transition, a division and a delineation of inter-establishment responsibilities hindered by the absence of a clear offer for services tailored to ID customers' needs (*Rapport spécial du protecteur du citoyen*, 2012), as well as a less developed expertise linked to ID in adult health services (Davies et al., 2011; Foley et al., 2012; Hudson, 2003; *Rapport spécial du protecteur du citoyen*, 2012). Thus, a need to improve services offered during and after the transition to adulthood remains to facilitate the transition to adulthood of the young adult with profound ID and his parents and the establishment of a new and more comfortable reality.

To meet this need, it is primordial to know the factors influencing the experience faced by families of young adults with profound ID to target issues tailored to their reality. However, few studies have documented the facilitators and barriers to the progress of the

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