



## Family beyond parents? An exploration of family configurations and psychological adjustment in young adults with intellectual disabilities

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### ABSTRACT

This research explores the family configurations of young adults with intellectual disability. Based on a sample of 40 individuals interviewed two times in a year, we found as many as four types of family configurations, with distinct compositions, and different types of social capital. This diversity is not without consequences for individual psychological adjustment. The results are discussed in the light of the configurational approach to families.

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## 1. Introduction

Family members are centrally important in psychological health, as the family is a primary resource of care and support (Fehr & Perlman, 1985; Furstenberg & Kaplan, 2004a, 2004b; Widmer, 2004). Despite the substantial attention given to family support for individuals with intellectual disabilities (ID), the diversity of such support was seldom taken into account empirically. Indeed, most studies focus on help from the nuclear family, especially from parents (Heiman & Berger, 2008), and do not consider the wider social and family contexts and their structural properties (Emerson et al., 2010; Faber & Wasserman, 2002). As family contexts have become more heterogeneous and open in recent decades due to the pluralization of life courses (Kohli, 2007; Shanahan, 2000), the focus on parents as single sources of support for adolescents and young adults with intellectual disabilities should be reconsidered. This contribution stresses the importance of including larger configurations of family ties when dealing with the interrelation between family support and the psychological adjustment of individuals with intellectual disabilities. It stresses that young adults with ID are embedded in various family configurations, which provide them with distinct types of social capital and which have consequences for their psychological adjustment.

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## 2. Literature review

### 2.1. Family support and psychological adjustment

A large body of literature in epidemiology and community psychology shows that family support positively affects psychological adjustment (Berkman, Glass, Brisette, & Seeman, 2000; Kawachi & Berkman, 2001). Closeness with mother and father is associated with higher psychological adjustment (Rothon, Goodwin, & Stansfeld, 2012). Overall, cohesive and supportive families have a beneficial effect on psychological adjustment of adolescents and young adults (Timko & Moos, 1996). However, parental support was found functionally distinct from that provided by siblings or friends, who usually provide some form of companionship (Barrera, Chassin, & Rogosch, 1993). Indeed, family roles insure a diversity of helps. Close family members provide a wide range of resources, while individuals who are less close provide either emotional support or services but generally not both (Agneessens, Waeye, & Lievens, 2006; Wellman & Worthley, 1989, 1990). Indeed, close kin hold a central position in providing social support and differ from friendship in both the amount and quality of support. Individuals—most often parents, siblings, and adult children—who provide instrumental help tend to offer emotional support also. However, for some individuals, extended kin also play a key supportive role (Agneessens et al., 2006).

Regarding psychological adjustment, it must be mentioned that all types of support have not been considered as equally important, as perceived emotional support holds a prominent place (Lin & Peek, 1999). Among the few studies approaching social support as a property of an extended family exchange system (for a review, Ferguson, 2006), high levels of support from a variety of family members reduce the likelihood that children experience depressive symptoms (Stevenson, 1998).

These results suggest that social support provided by parents to adolescents and young adults is embedded in broader networks of relationships, which structures matter (Faber & Wasserman, 2002). Several studies found that large networks were associated with higher psychological adjustment, while others found no difference or negative correlations between network size and psychological adjustment (Lin & Peek, 1999; Moren-Cross & Lin, 2006; Song, Son, & Lin, 2011). Adolescent and young adults well connected in peer networks present less depressive symptoms (Okamoto et al., 2011; Ueno, 2005). Studying friendship networks of adolescents, Ueno (2005) also showed that the relationship between having more friends and fewer depressive symptoms was largely mediated by a sense of belonging. Falci and McNeely (2009) highlighted a curvilinear effect of network size on depressive symptoms. Having only one friend is significantly found to be associated with depressive symptoms, but over-integration with too many friends also leads to higher depressive symptoms. These authors hypothesize that too many friends might be too demanding, but they also found that the negative effect of larger networks depends of the network density. It was hypothesized that dense configurations of ties, in which there are many connections between network members, protect individuals facing stressful events by providing more social support. Studies dealing with structural dimensions of support beyond the parental or the conjugal dyads are however scarce and provide mixed evidence (Lin & Peek, 1999). Falci and McNeely (2009) found nevertheless that highly dense networks protect against depressive symptoms among adolescent girls embedded in large network of friends. Very few studies, however, deal with the centrality of individuals in their personal networks. One (Cornwell, 2009) found that individuals with poor physical and mental health less often hold an intermediary position in their network, a situation which might well be too demanding for vulnerable individuals.

### 2.2. Family configurations and intellectual impairment

There is even less research on family support provided to individuals with ID and its consequences for their own psychological adjustment. During several decades, research has focused on how individuals with ID negatively affect their parents and siblings. Families of individuals with ID were thought to experience adverse costs consequent from over care. People with ID were considered as imposing high social and emotional costs and as being a source of stress (Eisenhower, Baker, & Blacher, 2009; Hatton et al., 2010; Hastings, 2002; Haveman, Van Berkum, & Reijnders Heller, 1997; Martorell, Gutiérrez-Recacha, Irazábal, Marsa, & García, 2011). On another hand, some authors underline the risk to overestimate the link between intellectual disability and parental well-being due to unaccounted socioeconomic factors (Emerson et al., 2010). Indeed, families taking care of a child with ID are significantly more likely to be exposed to socioeconomic disadvantages (Emerson & Hatton, 2008). Therefore, the burden of raising a child with ID may have been overemphasized (Hodapp & Dykens, 2009), as many family members also report life-enhancing benefits from raising a child with ID (Blacher & Baker, 2007; Green, 2007; Stainton & Besser, 1998; Taunt & Hastings, 2002).

Research focusing on individuals with ID suggests that they have fewer supportive relationships (Rosen & Burchard, 1990). Globally, adults with ID receive less emotional support and companionship from family members and friends than individuals without ID (Rosen & Burchard, 1990) and more support from care professionals (Forrester-Jones et al., 2006; Lunsby & Benson, 1999). Regarding psychological adjustment, one of the main studies dealing with the influence of social support in the context of ID showed that supportive social networks are associated with personal and family well-being (Dunst, Trivette, & Cross, 1986). More supportive social networks trigger a higher level of personal well-being. Relationships with friends who also had intellectual disabilities appeared to be protective against feeling helpless. Some differences between men and women have also been observed, as for women, being single was associated with greater well-being (Emerson & Hatton, 2008).

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