



Structural and functional characteristics of the social networks of people with mild intellectual disabilities

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ABSTRACT

In the research on people with intellectual disabilities and their social networks, the functional characteristics of their networks have been examined less often than the structural characteristics. Research on the structural characteristics of their networks is also usually restricted to the size and composition of the networks, moreover, with little attention to such characteristics as the variety, accessibility, length and origin of the relationships or the frequency and initiation of the contacts. A comprehensive examination of both the structural and functional characteristics of the social networks of 33 people with intellectual disabilities was therefore undertaken. The social networks of the individuals who all lived in the community varied from 4 to 28 members (mean 14.21); 42.65% of the network members were family members, 32.84% acquaintances and 24.51% professionals. Remarkable is the high frequency of contact with network members; the finding that the participants considered themselves to be the main initiator of contact more often than the other members of their networks as the main initiators; the high scores assigned to neighbours and professionals for functional characteristics; and the relatively low scores assigned to network members for the connection characteristic of the social networks. The important role of professionals in the social networks of people with mild intellectual disabilities and practical implications to facilitate their social inclusion are discussed.

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1. Introduction

In models of disabilities – for example, the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO, 2001) and the model of intellectual disabilities (ID) by the American Association on Intellectual and Developmental Disabilities (Luckasson et al., 2002), a shift from an intrapersonal approach to a social ecological approach is visible (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Community participation is considered an essential dimension of human functioning (Verdonschot et al., 2009) and social inclusion an important aspect of the individual's quality of life (Buntinx & Schalock, 2010). Being part of a social network of friends, family and people in the community is one of the main characteristics of successful social inclusion (Abbott & McConkey, 2006; McConkey & Collins,

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2010). And worldwide, the aforementioned shift has been translated into local and national policy leading to more and more people with ID living and working in the community.

Studies focussing on social networks of people with ID have examined the size, composition and amount of perceived support. This has been done using various methods: the Social Network Guide (Forrester-Jones et al., 2006), the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994) and the Social Support Self Report (Lippold & Burns, 2009; Lunskey & Benson, 1997). And while the social networks are mapped differently, the distinction of family, friends and professionals is consistently made. The social networks of people with ID can be analyzed in terms of structural and functional characteristics. Among the structural characteristics are the size of the network and frequency of interactions with network members while the functional characteristics are often divided into practical and emotional support (Lunskey, 2006).

With respect to the structural characteristics of the social networks of people with ID, not only differences between specific target groups have been investigated (Lippold & Burns, 2009; Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Galli Carminati, 2008) but also the associations of the social networks with such other variables as the characteristics of the respondents themselves (Dagnan & Ruddick, 1997) and the type of living situation (Forrester-Jones et al., 2006; McConkey, 2007; Robertson et al., 2001). Age and previous living accommodation are associated with variation in size and composition of social networks (Robertson et al., 2001). Dusseljee, Rijken, Cardol, Curfs, and Groenewegen (2011) found people with mild ID to have more friends (either with or without ID) than people with moderate ID although the majority of the people with mild ID still interacted very little with people without ID. Several studies found people living in a supported living accommodation to have more social contacts than people living in group homes or residential facilities (Forrester-Jones et al., 2006; McConkey, 2007; Robertson et al., 2001). However, physical presence within a community does not guarantee greater social inclusion and taking part in activities does not necessarily lead to meaningful social contact – particularly meaningful contact with individuals without ID (Ager, Myers, Kerr, Myles, & Green, 2001; Lippold & Burns, 2009). People with an ID living and working in society can still fall into isolation (Chenoweth & Stehlik, 2004). The social networks of people with ID are often small and the only contact with people without ID tends to be the family and professionals (e.g., Lippold & Burns, 2009; Verdonshot et al., 2009). To date, the main focus of research on the structural characteristics of social networks has been on the size and composition of the social network. Although this gives relevant information, there are more structural characteristics like (a) variety with regard to demographic characteristics; (b) accessibility; (c) structure of the ties, including length of the relationship, initiation of contact, frequency of contact and origin of the relationship (Baars, 1994). These characteristics are of importance because they provide insight into (a) the heterogeneity or homogeneity of the network; (b) the geographical distance between persons and their networks, possibly due to a move, which can contribute to social isolation; (c) the condition and nature of the ties, which provides information on the possibilities and limitations for the person with his network and the extent to which the client is able to maintain existing contacts and make new contacts (Baars, 1994). Interventions can be tailored to the results of analyses of these characteristics (van Asselt-Goverts et al., 2012).

With respect to the functional characteristics of the social networks of people with ID, research shows the main providers of both emotional and practical support to be support staff. Other network members with ID were the second most frequent providers of all types of support (Forrester-Jones et al., 2006). Obviously such support tends to be more reciprocal than the support provided by professionals. Meeting a need for “stability” and “connection” is underexposed in the research literature. According to Baars (1994), “stability” is the need to have ties which are maintained with a certain degree of preference as opposed to habit; “connection” is the need to belong, to find support and to make connections on the basis of shared interests, values and background. Connection should be assessed, as relationships should be promoted based on mutual interests and in committed environments (Lunskey, 2006).

People with mild ID living independently in the community are vulnerable with respect to their social networks. Previous research on the social networks of adults with mild ID living in the community (van Asselt-Goverts, Embregts, Hendriks & Frielink, under review) shows that (a) limitations in their adaptive behaviour (e.g., lack of social skills or difficulties with acceptance of disability) may hinder the development and maintenance of a social network; (b) professionals play a critical role in strengthening and expanding the social networks, but they often have too little time for this; (c) people with a mild disability often fall between the cracks when it comes to activities for the disabled versus nondisabled due to the mildness of their disabilities – this holds for both leisure time activities and the support provided (Embregts & Grimbé du Bois, 2005).

In sum and given the present policy, more and more young adults with ID are living in the community, but this physical inclusion does not lead automatically to social inclusion: research shows that social inclusion is limited (e.g., Dusseljee et al., 2011; Lippold & Burns, 2009; Verdonshot et al., 2009). One of the main characteristics of successful social inclusion is being part of a social network of friends, family and people in the community (Abbott & McConkey, 2006; McConkey & Collins, 2010). However, previous research shows that adults with mild ID living independently in the community are vulnerable with respect to their social networks (van Asselt-Goverts et al., under review). Therefore this research focuses on the social networks of people with mild ID. The functional characteristics of the social networks have been examined less often than the structural characteristics (Lunskey, 2006). And to date, the research on the structural characteristics has been on mainly the size and composition of the networks. Little attention has been paid to other structural characteristics such as the variety, accessibility, length and origin of the relationships or the frequency and initiation of the contacts while this information is critical for tailoring interventions to the strengths and weaknesses of the individual's social network. The aim of the present study was therefore to conduct a comprehensive examination of both the structural and functional characteristics of the

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