Social networks of people with mild intellectual disabilities

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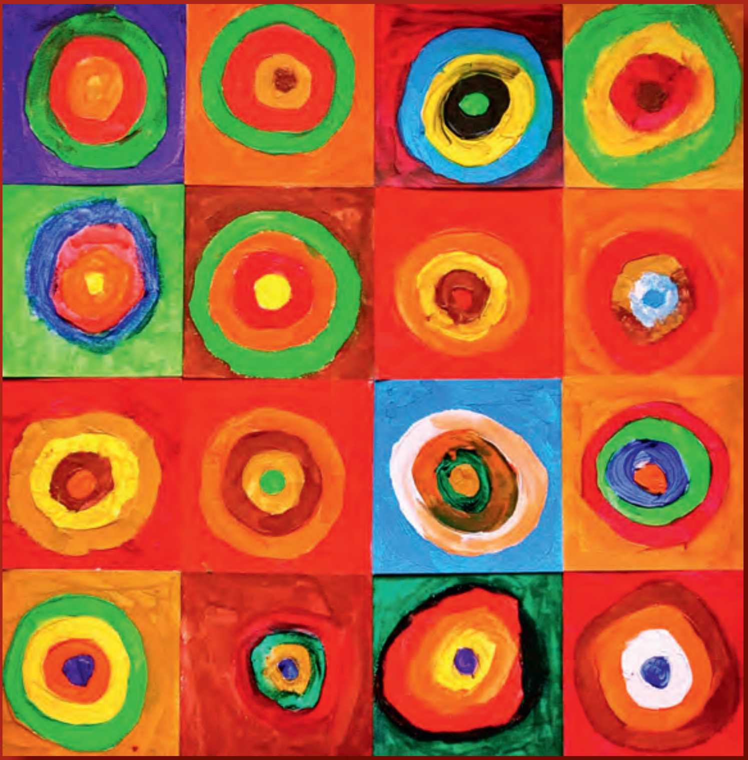
Social networks of people with mild intellectual disabilities: characteristics and interventions



Ida van Asselt-Goverts

Social networks of people with mild intellectual disabilities: characteristics and interventions

Ida van Asselt-Goverts

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characteristics and interventions

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Two people are better off than one,
for they can help each other succeed.
If one person falls,
the other can reach out and help. . . .
Three are even better,
for a triple-braided cord is not easily broken.

(Ecclesiastes 4: 9-12 New Living Translation)

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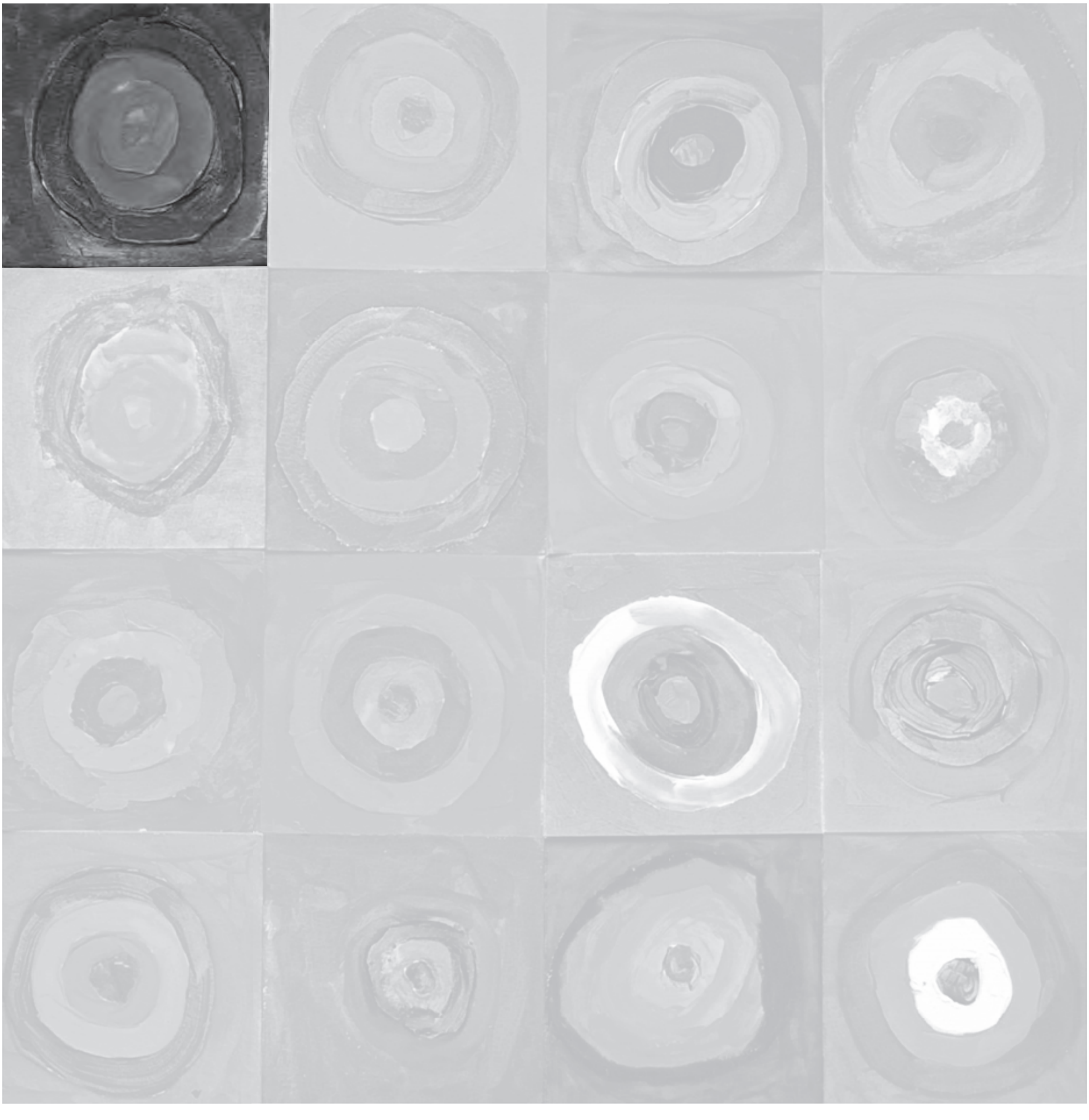

Chapter 1

General introduction

1.1 Introduction

Support for people with intellectual disabilities (ID) has greatly changed over the past decades. The focus has shifted from limitations in intelligence and skills to the individual functioning as a whole, using the concept of "quality of life" (QOL) to evaluate their general well-being. Social inclusion, participation and social networks are generally seen as important domains of QOL (Buntinx & Schalock, 2010). These changes have been translated into policy and legislation changes, resulting in more and more people with ID living in the community and receiving individualized support. Support should be provided primarily by family, friends and neighbours; only if that is not sufficient, are people considered for general or tailor made services (Wet maatschappelijke ondersteuning [Social Support Act], 2015). Research shows that there are benefits from community living for the social inclusion of people with ID (Forrester-Jones et al., 2006; McConkey, 2007; Robertson et al., 2001). However, physical presence in the community does not guarantee real social inclusion. Indeed, the social networks of people with ID are often small (e.g. Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009) and people with ID feel lonely more often (Sheppard-Jones, 2003; Valås, 1999). In the Netherlands, people with mild to borderline ID increasingly apply for professional support (Ras, Verbeek-Oudijk, & Eggink, 2013). This would seem to be related not only to the increased complexity of modern society and the growing expectation that people with ID will play a full part in society, but also to a lack of adequate support networks (Woittiez, Putman, Eggink, & Ras, 2014). Social networks are crucial in supporting people with mild to borderline ID so that they can cope with society and the growing expectations that they will participate and in doing so, enhance their well-being.

This thesis presents a series of studies on the social networks of people with mild to borderline ID living in the community and network interventions devised in order to enhance their social networks. This general introduction will provide the necessary background information about social inclusion, policy, people with ID, their social networks and network interventions. This chapter ends with the aims, research questions and an outline of the thesis.

1.2 Social inclusion

In models of disability — for example, the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO, 2001) and the model of ID proposed 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 et al., 2009). Both models include 'community participation' as an essential dimension of human functioning. The concept of QOL has also been introduced to evaluate the general well-being of people with disabilities. Social inclusion, participation and social networks are generally seen as important domains of QOL (Buntinx & Schalock, 2010). However, these terms are used interchangeably (Amado, Novak, Stancliffe, McCarren, & McCallion, 2013) and are not well defined (Brown, Cobigo, & Taylor, 2015; Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Overmars-Marx, Thomese, Verdonschot, & Meininger, 2014). Conceptual differences emerge around the scope (i.e. the activities, relationships and environments that social inclusion encompasses), the setting (i.e. integrated as well as private or segregated settings), and the depth of social inclusion (i.e. subjective and/or objective measurements) (Simplican, Leader, Kosciulek, & Leahy, 2015). Some researchers have defined social inclusion by its opposite, social exclusion, which is, in turn, defined as a lack of opportunities to participate in social, economic and/or political life (Cobigo, et al., 2012; Moonen, 2015). However, it is a simplification to say that someone is either included or excluded, because it is not a dichotomous phenomenon (Cobigo et al., 2012). Instead, the level of inclusion may vary across roles and environments, and over time (Cobigo et al., 2012). According to Simplican and colleagues (2015) social inclusion focuses on two domains, social relationships and community participation that mutually support each other. In line with previous models of disability, they propose an ecological model. In this model, social inclusion is influenced by multiple factors, including individual (e.g. IQ, self-esteem, self-motivation), interpersonal (e.g. relations with and attitudes of network members), organizational (e.g. culture of the organization and mission statements), community (e.g. availability and access to services and transportation) and socio-political (e.g. laws, market forces) factors (Simplican et al., 2015). These factors can promote or impede social relationships and community participation. With respect to social relationships Simplican and colleagues (2015) distinguish three characteristics: (a) category (i.e. the kinds of people in the network); (b) structure (e.g. length, origin and frequency); and (c) function (e.g. emotional, practical and informational support). Community participation is also characterized by three aspects: (a) category (e.g. leisure time, employment, education, access to goods and services, cultural activities); (b) structure (i.e. segregated, semi-segregated or integrated settings); and (c) level of involvement (i.e. present, encounter or participation). This model specifies the domains and components of social inclusion. It does not specify general criteria, such as whether people are socially included or not, because people differ in their capabilities and choices regarding social relationships and community participation (Pelleboer-Gunnink, van Weeghel, & Embregts, 2014). Therefore it is crucial to consider the perceptions and opinions of people with ID themselves.

In QOL research the question has already arisen whether people with ID are able to reliably evaluate their own subjective well-being or whether such information is better provided via proxies. Even though the conclusions of comparable studies are contradictory (Cummins 2002; Nota, Soresi, & Perry, 2006; Schmidt et al. 2010; Verdugo, Schalock, Keith, & Stancliffe, 2005), the emerging consensus is that people with ID should be asked to give their own views (Roeleveld, Embregts, Hendriks, & van den Bogaard, 2011; Verdugo et al., 2005). The principle that no policy or research can be developed without the involvement of the person concerned is emphasized in the slogan 'Nothing about us, without us' (van Hove, 2014). Thus, people with ID participate more and more in research and training, for instance as a participant, co-researcher or trainer (Embregts et al., 2015; Embregts & Verbrugge (submitted); McDonald, Kidney, & Patka, 2013; O'Brien, McConkey, & García-Iriarte, 2014; Puyalto, Pallisera, Fullana, & Vilà, 2015; van Hove, 2014).

1.3 Policy with respect to people with disabilities and social inclusion

The importance of social inclusion, participation and social relationships is acknowledged worldwide, for example in the United Nations Convention of the Rights of Persons with Disabilities (United Nations, 2006) and in policy in many countries, for instance in the United States with regard to creating opportunities for community living (Hewitt, Nord, Bogenschutz, &

Reinke, 2013) and in the United Kingdom, where people with disabilities are considered as citizens participating in all aspects of community and in control of the decisions in their lives (Department of Health, 2009). Worldwide, over recent decades, large institutions has been closed in favour of community-based support; the so-called deinstitutionalization (Beadle-Brown, Mansell, & Kozma, 2007; Lemay, 2009). In the Netherlands as well, an increasing number of people with ID are living independently in the community with the aim of participating in society (Lub, Uyterlinde, & Schotanus, 2010). Physical presence in the community, however, does not guarantee greater social inclusion, just as taking part in an activity does not guarantee meaningful social contact (Ager, Myers, Kerr, Myles, & Green, 2001).

At the present time in the Netherlands — but much earlier the Nordic countries (Tøssebro et al., 2012) — local government is becoming more and more the core provider of services, in a process of decentralization. In this context major changes were recently implemented in legislation regarding the care and support of people with ID. The Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektenkosten, AWBZ) was until 2015 the insurance scheme for long-term care for people with ID. It has now been replaced by the Long-term Care Act (Wet langdurige zorg) for people who need the most intensive forms of care. Support provided in the home setting has been placed under the responsibility of local authorities, in accordance with the Social Support Act (Wet maatschappelijke ondersteuning, Wmo, 2015). This choice was based on the assumption that, compared to the national government, local authorities are more able to stimulate participation and are better attuned to specific local situations and citizens' needs and, due to this, are able to provide services more efficiently (Dijkhoff, 2014). An important change is that the Wmo, in contrast to the AWBZ, does not prescribe entitlements to specific facilities for citizens, but instead places a general obligation on municipalities to provide social care and support, including general and tailor-made services (Dijkhoff, 2014). The Wmo expects independence from public services, self-reliance and 'personal strengths' and, if necessary, support from a person's own informal networks (Grootegoed & van Dijk, 2012; Wet maatschappelijke ondersteuning, 2015). However, the aims of these policies are causing major challenges due to the vulnerability of people with ID and their networks. In the next section the characteristics of people with ID are outlined, followed by a description of their networks in section 1.5.

1.4 People with intellectual disabilities

The Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition (DSM-5), defines intellectual disabilities as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. Three criteria should be met: (a) deficits in intellectual functions, confirmed by both clinical assessment and an individualized standardized IQ test (IQ < 70); (b) deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility; (c) onset in the developmental period (American Psychiatric Association, 2013, p. 17). In the fourth edition of the DMS the levels of severity of the ID were defined by IQ. People with IQ 55-70 had a mild ID; people with IQ 40-55 had a moderate ID; people with IQ 25-40 had a severe ID; and people with IQ < 25 had a profound ID (American Psychiatric Association, 1994). However, in the DSM-5, the various levels of severity are not defined on the basis of IQ scores, but on the basis of adaptive functioning (i.e. functioning in the conceptual, social and practical domains). This is because it is this adaptive functioning that determines the level of support required. In de DSM-5 mild ID is characterized by a set of impairments. In adults with mild ID, abstract thinking, executive function (i.e. planning, priority setting and cognitive flexibility) and the functional use of academic skills are impaired (cognitive functioning). They also experience limitations in social interactions, such as in perceiving social cues, in regulating emotion and behaviour and in understanding of risk (social domain). Moreover, they are able to function appropriately in terms of personal care and in jobs that do not emphasize conceptual skills, but they need support in, for instance, home and child care organization, money management and in making difficult decisions (American Psychiatric Association, 2013). Moreover, research shows that people with ID experience lower self-esteem (Valås, 1999), less autonomy and decreased well-being (Sheppard-Jones, 2003). In the Netherlands there are about 142,000 people with ID (IQ < 70) amongst which 74,000 people have a mild ID (Woittiez, Ras, Putman, Eggink, & van der Kwartel, 2015). In the Netherlands people with a borderline ID (IQ 70-85) who have additional problems in adaptive behaviour also receive support from organizations for people with ID (Moonen & Verstegen 2006). Just as in people with IQ < 70 they benefit from treatments which are characterized by repetition, concretization and small steps (van Nieuwenhuijzen, Orobio de Castro, & Matthys, 2006). Approximately 2.2 million people have an IQ between 70 and 85, but it is difficult to say how many of them have additional problems in adaptive behaviour (Woittiez, et al., 2015). However, the number of people receiving support from care organizations is known. In 2011 almost 166,000 people with ID received care funded by the AWBZ, of whom 46% required care in their home setting (i.e. community based care) (Ras et al., 2013). Over 72,000 people had mild ID (IQ 50-69) and almost 37,000 people had a borderline disability (IQ 70-85) (Ras et al., 2013). The number of people applying for care rose between 2007 and 2011. For people with mild ID there was a rise of 7% and for people with borderline disability of 15% (Ras et al., 2013). According to Woittiez et al. (2014) changes in the care system and social developments have led to this increase in demand for care. Changes in the care system include greater access to care, the growing availability of care and early assessments. Social developments include today's more complex modern society, the growing expectation that people with ID will play a full part in society and a lack of adequate support networks (Woittiez, et al., 2014). It is not possible to change the complexity of modern society, but social networks can be altered and they are crucial in helping people with mild to borderline ID to cope with the challenges of living more integrated in society. Such alterations to their social network can enhance people's well-being. Therefore this thesis will focus on the social networks of people with mild to borderline ID, living in the community. What are the characteristics of their networks and how can these networks be enhanced using network interventions? In the next section previous research on these themes is presented.

1.5 Social networks of people with intellectual disabilities and network interventions

A social network can be defined as all those people with whom someone maintains direct, permanent and important links (Baars, 1994). Studies focusing on the social networks of people with ID have examined the size, composition and amount of perceived support using various methods such as the Social Network Guide (Forrester-Jones et al., 2006), the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994), the Support Interview Guide

(Llewellyn & McConnell, 2002) and the Social Support Self Report (Lippold & Burns, 2009; Lunsky & Benson, 1997). While social networks have been mapped differently, the distinction between the categories such as family, friends and professionals has been made consistently. The network can be divided into two areas (e.g. van Asselt-Goverts et al., 2012), the formal network (i.e. the network of professionals) and the informal network (i.e. family, friends, neighbours, colleagues and other acquaintances) and analysed in terms of structural and functional characteristics. Among the structural characteristics are the size of the network and the frequency of interactions with network members. The functional characteristics (i.e. social support) are often divided into practical and emotional support (Lunsky, 2006).

With respect to the structural characteristics of the social networks of people with ID, differences between specific target groups have been investigated (Lippold & Burns, 2009; Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Galli Carminati, 2008) and associations made with the type of living situation (Forrester-Jones et al., 2006; McConkey, 2007; Robertson et al., 2001). People with mild ID appear to have more friends (either with or without ID) than people with moderate ID, although the majority of people with mild ID still interact very little with people without ID (Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011). People living in a supported living accommodation seem 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, their social networks are often small and the only contact with people without ID tends to be with family and professionals (e.g. Lippold & Burns, 2009; Verdonschot et al., 2009). The size of the network found in the literature varies from a median of six members (Robertson et al. 2001) to an average of 11.67 (Lippold & Burns, 2009) and 22 (Forrester-Jones et al., 2006) for people with ID living in the community. 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 such as accessibility, length of the relationship, initiation or frequency of contact (Baars, 1994). These characteristics are of importance because they provide insight into the condition and nature of the ties which, in turn, provides information about the possibilities and limitations for that person of his network and the extent to which the person is able to maintain existing contacts and make new contacts (Baars, 1994).

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). Meeting a need for "stability" and "connection" has not had much consideration in the 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 and "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 because relationships should be promoted based on mutual interests and in committed environments (Lunsky, 2006).

It has been shown that social support benefits both physical and mental health and is related to lower rates of morbidity and mortality in the general population (e.g. Cohen & Wills, 1985; Holt-Lunstad, Smith, & Layton, 2010; Umberson & Montez, 2010). This positive influence of social support on health can be explained by two models. The first model is the main- or direct effect model. A person's degree of integration in a large network, influences health (Cohen & Wills, 1985). The second model is the buffering model. Perceived social support protects people from the potentially negative effects of stressful events, if the support is responsive to the needs elicited by the stressful events (Cohen & Wills, 1985). Also, for people with ID, social support can act as a buffer between the impact of stress and the mental health consequences (Scott & Havercamp, 2014). Likewise, access to social support has a buffering effect on the association between child behaviour problems and stress for parents with ID (Meppelder, Hodes, Kef, & Schuengel, 2015). Finally, there is some evidence for an association between social support and QOL of adults with ID (e.g. Bramston, Chipuer, & Pretty, 2005; Lunsky & Benson, 2001; Miller & Chan, 2008).

Therefore, it is necessary to enhance the networks of people with mild ID if, according to the persons themselves, they provide insufficient support. It is crucial to focus on their own perspectives, because they are the experts on their feelings, experiences and thus on their own opinions (Cambridge & Forrester-Jones, 2003; Forrester-Jones et al., 2006) and they are reliable reporters of social support (Lunsky & Benson, 1997). However, research on social networks from the perspective of the person with ID is sparse (Emerson & Hatton, 2008). In particular, research on their perceptions and valuations (e.g. satisfaction and wishes regarding their networks) is lacking. Research shows that people with ID feel lonely more often (Sheppard-Jones, 2003; Valås, 1999) with up to half of them reporting feelings of loneliness (Amado, Stancliffe, McCarron, & McCallion, 2013; Gilmore & Cuskelly, 2014; McCarron et al., 2011; Stancliffe et al., 2007).

Support staff can play an important role in the facilitation of social inclusion (Abbott & McConkey, 2006; Todd, 2000; van Alphen et al., 2009). If social networks are small and social support is perceived as insufficient, support staff can undertake network interventions to enhance social networks. Various network interventions are described in the general literature on social networks (Heaney & Israel, 2008) and, more specifically, in the field of mental health care (Biegel, Tracy, & Corvo, 1994; Pinto, 2006). In all cases, a distinction between expanding the social network with new contacts and strengthening existing ties is made (Biegel et al., 1994; Pinto, 2006).

However, research shows that staff members pay greater attention to care tasks than to social inclusion tasks (McConkey & Collins, 2010). Research on the experiences of support staff with network interventions and their effect for people with ID is scarce. Howarth, Morris, Newlin and Webber (2014) conducted a systematic review of this subject and could only include 11 studies. In six of these studies positive outcomes were found for the social participation of the person. Person-Centered Planning (PCP) (Robertson et al. 2006), alteration of activity patterns (Ouelette, Horner, & Newton, 1994) and semi-structured group programs including exercises for improving social skills (McConnell, Dalziel, Llewellyn, Laidlaw, & Hindmarsh, 2009; McGaw, Ball, & Clark, 2002; Ward, Windsor, & Atkinson, 2012) appear to be the most effective interventions (Howarth et al., 2014).

1.6 Present thesis: aims, research questions and outline

In summary, in policy and practice there is increased attention on and recognition of the importance of social inclusion, participation and social networks. However, people with mild to borderline ID increasingly apply for professional support, partly due to the lack of adequate networks (Woittiez et al., 2014). Therefore, this thesis focuses on the networks of people with mild to borderline ID. For the sake of readability we use 'mild ID', by which we generally mean 'mild to borderline ID'. Until now a comprehensive picture of the characteristics of the social networks of people with mild ID from their own perspective has been lacking. First, research on social networks and well-being from the perspective of the people with ID themselves is sparse (Emerson & Hatton 2008), even though it is important that they are asked to give their own views (e.g. Roeleveld et al., 2011, Verdugo et al., 2005). Next, the functional characteristics of the social networks have been examined less often than the structural characteristics (Lunsky, 2006) and research on the structural characteristics has been mainly into the size and composition of the networks. Little attention has been paid to other structural characteristics, such as accessibility, length of the relationships or the frequency and initiation of the contacts. In addition, little attention has been paid to the satisfaction of people with ID with their social networks or their wishes with regard to such. There is some evidence of an association between perceived support and QOL (e.g. Bramston et al., 2005; Miller & Chan, 2008; Lunsky & Benson, 2001), but systematic investigation of the characteristics of social networks in relation to their perceived QOL is lacking. Additionally, data on both structural and functional characteristics are difficult to interpret because normative data are lacking. Finally, little is known about the experiences of people with mild ID and their support workers with network interventions and the effect of these interventions.

Therefore this thesis has two aims. The first aim is to provide a comprehensive picture of the specific network characteristics from the perspectives of people with mild ID themselves. The second aim is to gain insight into network interventions and how well they succeed. With these aims in mind, we pose the following research questions. What are the specific network characteristics and specific network perceptions of people with mild ID? What are the experiences of professionals with regard to strengthening and expanding the social networks of clients with mild ID? What are the results of a social network intervention, aimed at enhancing social networks of people with mild ID?

We focus on the social networks of adults with a mild ID, without additional behaviour problems, living in the community on their own (i.e. not with parents, not in group homes) receiving visiting support from professionals. The thesis consists of two parts. The first part contains three chapters (chapters 2, 3 and 4) and focuses on the network characteristics from the perspective of people with mild ID. We used the Maastricht Social Network Analysis (MSNA) (Baars, 1994) adapted for people with mild ID (van Asselt-Goverts et al., 2012) to map the structural characteristics (e.g. accessibility, length of the relationship, initiation and frequency of contact) and functional characteristics (i.e. affection, connection, preference and practical/informational support) of the social networks of the participants. In this first part of the thesis a mainly quantitative approach was used. In chapter 2 we conduct a comprehensive examination of both the structural and functional characteristics of the social networks of people with mild ID. In chapter 3 we investigate the degree of satisfaction and the wishes of people with mild ID for their networks. We also examine the characteristics of the social networks in relation to network satisfaction and perceived QOL. In chapter 4 we compare the networks of people with mild ID, people with Autism Spectrum Disorders (ASD) and a reference group, to gain insight into the specific network characteristics and perceptions of people with mild ID. Because chapters 2, 3 and 4 can be read as separate articles, some overlap in the description of the studies could not be avoided. The second part of the thesis focuses on network interventions. In this part a mainly qualitative approach is used. In chapter 5 we explore the experiences of professionals in strengthening and expanding the social networks of clients with mild ID using group interviews. In chapter 6 we examine the results of an intervention aimed at strengthening or expanding the social networks of people with mild ID, from different perspectives (i.e. participants with ID, their support staff and trainers), using mixed methods (i.e. questionnaires and interviews) in a multiple case analysis. Finally, the general discussion in chapter 7 summarizes the main findings of the thesis, reflects on the strengths and limitations, and describes implications for future research, policy, practice and education.

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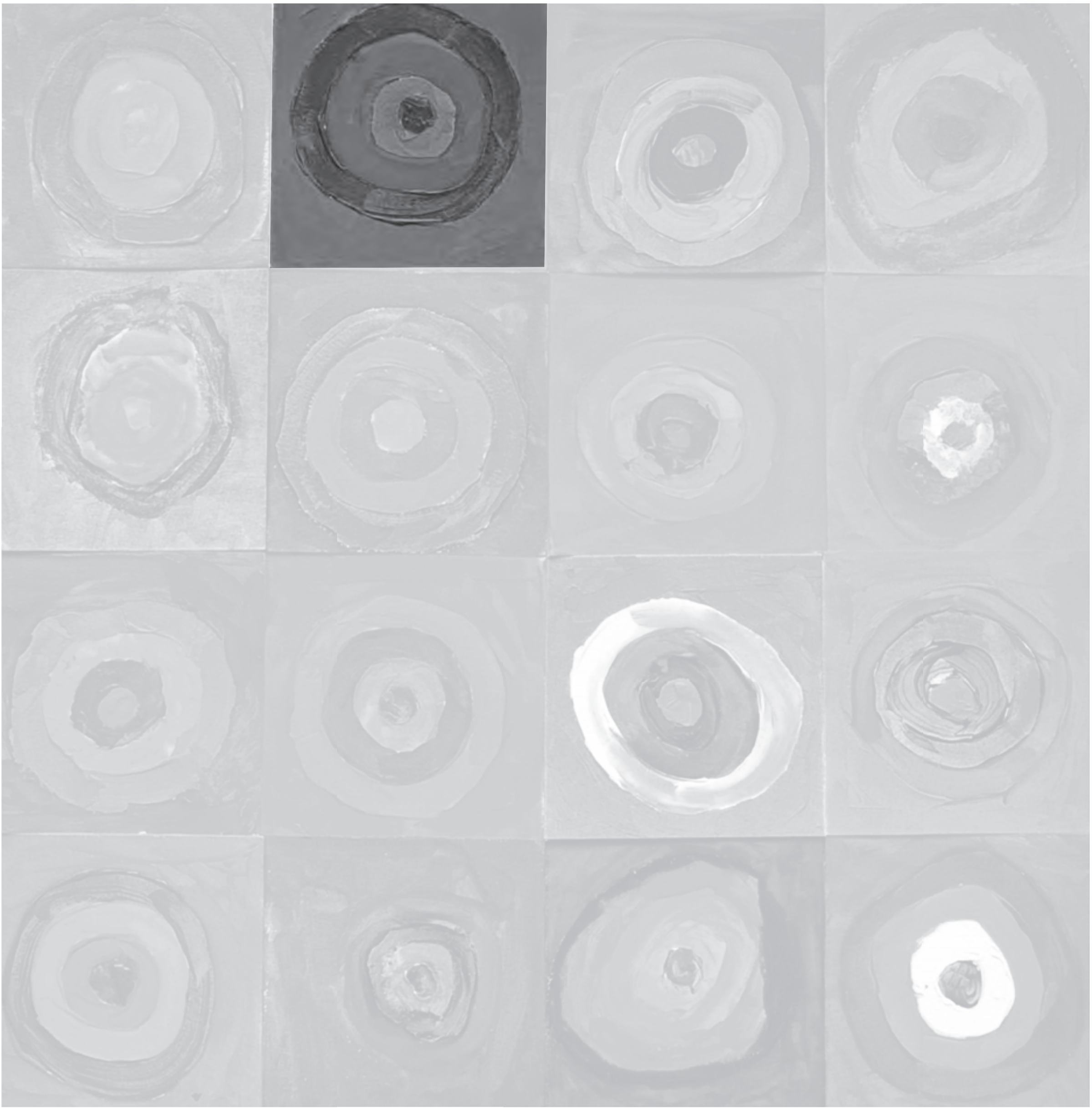

Chapter 2

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 four 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.

2.1 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, 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; Lunsky & 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 (Lunsky, 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; Verdonschot 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 (Lunsky, 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, 2014) 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 & Grimbel 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; Verdonschot 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., 2014). 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 (Lunsky, 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 social networks of people with ID from the perspectives of people with ID themselves. The following research questions will be answered in the present study:

1. How do people with mild ID describe the structural and functional characteristics of their social networks?
2. Do groups of network members (i.e. family, acquaintances and professionals) differ on structural and functional characteristics, according to people with mild ID?
3. Are there differences between the functional characteristics (i.e. affection, connection, preference and practical/informational support) within each group of network members?

2.2 Method

2.2.1 Participants and setting

Clients from seven care organizations, located in the southeast of the Netherlands, participated in this research. Clients met the inclusion criteria if they had (a) a mild to borderline ID; (b) an age between 19 and 36 years; and (c) an independent residence of at least two years in the community (i.e. lived in the community alone, with a partner, friend or children). People who lived in a residential facility were thus excluded from participation in the present research. We started the study with an accidental sample of 38 participants. To obtain a sufficiently large sample, all persons who signed up were approached. One participant could not be reached after signing up; another cancelled the appointment; and another three were not included in the analyses due to incomplete data. We thus had a total of 33 participants and the number of respondents per organization varied from two to seven. Sixteen men and 17 women participated. The average age was 28.88 years. Approximately half of the participants had a partner ($n = 17$), but not all were living together with the partner. Most of the participants were living alone ($n = 23$); others were living with their partners ($n = 7$) and/or with their children ($n = 3$). Regarding the work situation: 78.79% of the participants were employed or had activities outside the home during the day; the remaining 21.21% were either unemployed, unable to work and/or responsible for housekeeping in the home.

2.2.2 Instrument: Maastricht Social Network Analysis

The Maastricht Social Network Analysis (MSNA) (Baars, 1994) is an instrument which can be used to map the structural and functional characteristics of a social network. A list of important network members is first constructed and can include: family members, friends, colleagues, neighbours, other acquaintances and professionals (e.g. support staff, therapists, social workers, coaches). Next, each member of the network is scored with respect to a number of structural characteristics: demographic characteristics, accessibility (i.e. geographical distance between participant and network member), length of the relationship, initiation of contact, frequency of contact and origin of the relationship. Demographic characteristics included age (younger or older than 35 years), civil status (having a partner or not), work situation (employed/having activities outside the home or not), IQ (having ID or not). Accessibility was coded as network member living in the same town or not. Length of the relationship was indicated in years. Origin of the relationship was measured using an open-ended question (*'How did you meet this network member?'*). Initiation of contact was divided into four categories: a participant can either view himself or a network member as the main initiator of the contact, but they can also view the initiation as being reciprocal or non-active. Frequency of contact (measured as number of times per year) included frequency of face-to-face contact, frequency of contact via telephone and frequency of internet contact. Each relationship was next scored along a five-point scale with respect to a number of functional characteristics, namely the supportiveness of the contact operationalized using the following four dimensions: affection (e.g. feeling safe and secure with the person, loving the person), connection (e.g. liking the same things), preference (e.g. preference for contact with the person, liking the contact), and practical/informational support (e.g. being helped by the person when you don't know something or aren't able to do something). With respect to the reliability and validity of the MSNA, the following served as starting points: (a) the person gives only information on network members with whom there is a direct connection; (b) the information obtained in such a manner is of a largely objective, factual nature; and (c) the person gives only information which is known for certain and omits anything which is uncertain (Baars, 1994).

For the present study, the original form of the MSNA was adapted for use with people with mild ID by simplifying the questions and using visualization.

First, a genogram (i.e. family tree) was used to map the characteristics of the participant's family relations. Second, an ecogram was used to visualize the rest of the social network: three expanding circles are placed around the name of the participant to map friends, neighbours, colleagues, other acquaintances and professionals in the social network. The participant was asked to point to where a network member's name should be written. The more important the network members were, the closer their names were written to the name of the participant. Third, the five-point scale used to measure the functional characteristics of the participant's social network was visualized by positioning the response possibilities on the five steps of a stairway; the higher the score, the higher the step on the stairway.

2.2.3 Procedure

The study was approved by the scientific and ethics committee from one of the seven participating organizations, *Dichterbij*, from which seven clients participated (21.21% of the total number of participants). The support staff from the organizations were asked to approach clients meeting the inclusion criteria to participate in the research. Next, the 33 participants, all with mild to borderline ID, gave their permission. Written consent was received from all of them. The interviews were conducted by trained bachelor students at the HAN University of Applied Sciences. At the start of an interview, the participant was informed about the purpose of the study, the anonymous treatment of responses and the possibility to stop the interview at any time. To enhance the reliability of our data collection, we used an interview protocol and accompanying instruction manual (van Asselt-Goverts et al., 2012). The bachelor students were trained on the use of the protocol and interview conduct. The interviews were voice recorded and the responses of the participants were also noted during the actual interviews.

2.2.4 Data analysis

The data were processed and analyzed using SPSS. Network members were included in the dataset if they were older than 12 years. With respect to the first research question (i.e. the structural and functional characteristics of the social networks) we calculated *for each participant:*

1. The absolute and relative number of network members for the specific groups and subgroups: the family (divided into subgroups

of partner/children, parents, brothers/sisters and other family members); acquaintances (divided into subgroups of friends, colleagues, neighbours and other acquaintances); and professionals.

2. The distribution (i.e. percentages) of the demographic characteristics (age, civil status, work situation and ID), accessibility, origin of the relationship and initiation of contact for each of the groups and subgroups of network members. In order to do this, the answers on the question with respect to the origin of the contact – the only open-ended question – were coded and clustered into 10 categories, namely partner, family, other people, school/work, internet, casual outdoor encounters, sports/clubs, neighbourhood, holiday and other codes. The assignment of the codes to categories was discussed with several researchers involved in the research project. In all of these calculations the scores for each network member were weighted equally to the score for the total group of network members, so the number of network members belonging to the subgroup was taken into account in calculating the scores for the total group of network members for each participant.
3. Mean scores for each of the groups and subgroups of network members with respect to the frequency of contact, length of the relationship and functional characteristics. In these calculations, each network member was also weighted equally.

In addition, we calculated the mean scores for each of the aforementioned characteristics *over the total group of participants* for the different groups and subgroups of network members. Obviously, all of the participants were weighted equally here, regardless of the number of network members in the network.

To answer the second research question, the differences between the within-subjects factor ‘groups of network members’ (i.e. three levels: family, acquaintances and professionals) on several structural and functional characteristics were analyzed in a repeated measures ANOVA (GLM). Post hoc pairwise comparisons with a Bonferonni correction were then conducted. If it was unnecessary to compare the three levels, paired sample t-tests were used to compare the means on these structural characteristics. For instance, with respect to length of relationships it was unnecessary to compare acquaintances with family, because it was obvious that people knew their family members their entire lives.

Finally, to answer the third research question mean scores on the different functional characteristics (i.e. four levels: affection, connection, preference and practical/informational support) for each group of network members were also analyzed as a within-subjects factor.

2.3 Results

2.3.1 Structural characteristics of the social networks

Size and composition

The social networks of the participants varied from four to 28 members (mean 14.21). Almost half of the network members were family members (42.65%): partners and children (4.51%), parents (10.59%), brothers and sisters (8.39%) and other family (19.16%). Acquaintances constituted 32.84% of the network members: friends (19.91%), colleagues (5.10%), neighbours (1.83%) and other acquaintances from, for example, a sports club (6.01%). The remaining 24.51% of the network members were professionals, including support staff, general practitioners and coaches. One of the 33 participants in this study had no family members; four had no acquaintances in their networks whatsoever.

Demographic characteristics and accessibility

Table 1 gives detailed information on the demographic characteristics of the members of the social networks (e.g. age, civil status, work situation, IQ) along with their accessibility, operationalized in terms of living in the same town as the participant or not. Relative to acquaintances, family members were more frequently older than 35 years, $t(27) = 3.549$, $p = .001$. The family members also had a partner more frequently than the acquaintances, $t(27) = 3.977$, $p < .001$. Looking at the work situations of the network members, approximately 75% of the partners, friends, neighbours and other acquaintances were employed or had activities outside the home during the day; for parents, this percentage was lower – possibly due to their age; for siblings, the percentage was higher (90.00%). The difference in work situation between family and acquaintances in general, however, was not significant, $t(27) = -1.756$, $p = .090$.

Table 1 *Demographic characteristics and accessibility of network members (mean %)*[a]

	Age		Civil status		Work situation		IQ		Accessibility	
	< 35	> 35	Partner	Single	Work[b]	No Work[b]	ID	No ID	Same town	Elsewhere
Family	33.72	65.61	66.61	32.61	65.77	30.11	11.36	88.38	30.95	66.74
Partner/children	70.59	29.41	97.06	2.94	73.53	26.47	58.82	35.29	82.35	17.65
Parents	0.00	100.00	55.56	44.44	51.85	48.15	3.70	96.30	40.74	59.26
Brothers/Sisters	68.67	31.33	64.00	34.00	90.00	10.00	6.00	94.00	30.00	62.00
Other Family	36.01	62.60	71.65	28.35	59.24	29.89	8.49	91.51	20.04	78.73
Acquaintances	54.76	41.45	34.13	60.35	81.08	14.61	28.74	70.91	53.85	45.81
Friends	60.90	39.10	29.73	68.42	75.93	19.36	27.78	72.22	50.57	49.43
Colleagues	40.91	50.00	37.12	53.79	100.00	0.00	25.76	74.24	34.85	65.15
Neighbours	50.00	50.00	28.57	71.43	78.57	21.43	57.14	42.86	100.00	0.00
Other acquaintances	70.18	25.97	50.68	45.48	77.55	9.82	8.79	87.36	46.85	49.30

[a] Category totals which differ from 100% reflect missing data (i.e. the participant did know the network member's age, civil status, etc); [b] "Work" means work or activities outside the home during the day.

Almost 60% of the partners/children and neighbours had an ID while some 25% of the colleagues and friends had an ID. The percentage of parents, brothers/sisters, other family members and other acquaintances with an ID was lower. The percentage of network members with no ID was significantly higher for the family than for acquaintances, *t*(27) = 2.749, *p* = .011. With respect to accessibility of the network member, family members lived less often in the same town as the participant when compared to acquaintances, *t*(27) = -3.937, *p* = .001.

Length of the relationships

Here we describe the length of the contacts with partners; with friends, colleagues, neighbours and other acquaintances; and with professionals. The participants knew their partners for an average of 5.42 years (range of 4 months to 14 years). They knew their friends for an average of 6.85 years (range of 0.63–20.67 years), their neighbours for an average of 5.71 years (range of 1–16 years) and the other acquaintances in their social networks for an average of 6.12 years (range of 1.86–27.00 years). The length of the relationships with both colleagues and professionals was less long, with means of 3.23 and 3.19 years, respectively. Despite the relatively short duration of the contact with colleagues, the participants knew their acquaintances significantly longer than the professionals, *t*(25) = 2.154, *p* = .041.

Origin of the relationships

In this section, the origins of the contacts with the subgroups of partners, friends and other acquaintances are described. The responses of the participants to the open questions posed during the interviews showed school/work to be the main origin of the relationship with the partner (29.41%), followed by internet (23.53%) and casual outdoor encounters such as going out, festival attendance and simply hanging around on the street (17.65%). Participants also met their friends most frequently at school or work (28.02%) but also via other people (18.47%), in the neighbourhood (17.95%) or at a sports club or some other club (12.06%). The origin of the relationships with the other acquaintances in the social networks of the participants was another person for 47.47% of the relationships. In 18.41% of the relationships, the origin was a casual outdoor encounter. In 12.89%, the origin was the neighbourhood. And in 9.62%, the origin was a sports club or some other club.

Frequency of contact

Of the 17 participants with a partner, 12 saw their partner every day. Other network members were also seen with a high frequency: parents and friends almost twice a week; siblings, other acquaintances and professionals about once a week; and colleagues and neighbours some three to four times a week. There was a significant main effect of network group on the frequency of face-to-face contact, *F*(2,48) = 5.594, *p* = .007. Participants saw acquaintances significantly more often than professionals on average, *p* = .018.

Participants spoke most often on the phone with their parents (three times a week) and their partners and friends (two times a week). They spoke less often but still every other week with siblings. The frequency of telephone contact did not differ significantly for the three groups of network members. The participants most often had internet contact with their friends (1.5 times a week) and less often with professionals (two times a year). There were significant differences between the groups of network members for internet contact, *F*(1.08, 15.17) = 5.774, *p* = .027. Post hoc comparisons showed that the participants had nearly significantly (*p* = .071) more internet contact with acquaintances than with professionals. For more detailed information on the frequency of contacts, see Table 2.

Table 2 *Frequency of the contact (times a year)*

	Face-to-face	Telephone	Internet
Family	81.61	102.48	23.67
Partner/children	290.00	109.27	8.38
Parents	98.31	151.72	31.76
Brothers/Sisters	58.55	20.12	27.70
Other Family	28.15	58.61	19.80
Acquaintances	116.96	97.41	52.78
Friends	95.88	108.51	78.04
Colleagues	170.27	40.93	44.24
Neighbours	211.86	44.64	0.00
Other acquaintances	63.23	81.83	18.74
Professionals	65.95	13.11	2.02

Initiation of contact

As can be seen from Table 3, the initiation of contact was considered reciprocal in almost 50% of the relationships for all of the subgroups we identified with the exceptions of brothers and sisters, other family members and other acquaintances. The category of inactive initiation (neither the participant nor the network member explicitly takes the initiative of contact) was relatively high for the other family members, other acquaintances, neighbours and colleagues (range of 17.28–37.88%). In such cases, the individuals see each other along with the others in a group, at a club, on the street or at work.

The results in Table 3 show those participants who judged the initiation of contact within their social network to be neither reciprocal nor inactive to perceive themselves as the main initiator of contact more often than the other members of their social networks. This difference was significant for both the family members within the social network, *t*(31) = 3.499, *p* = .001, and the acquaintances, *t*(28) = 2.504, *p* = .018. Comparison of the initiation of contact across the three groups (i.e. family, acquaintances and professionals) revealed no significant differences.

Table 3 *Initiation of contact (mean %)**

	Reciprocal	Participant	Network member	Inactive
Family	38.21	36.85	10.12	9.48
Partner/children	50.00	26.47	5.88	5.88
Parents	48.15	38.89	9.26	0.00
Brothers/Sisters	32.67	40.00	13.33	4.00
Other Family	29.96	37.87	8.71	17.28
Acquaintances	49.44	24.88	6.71	14.33
Friends	48.01	26.94	7.87	11.98
Colleagues	48.48	9.09	4.55	37.88
Neighbours	50.00	14.29	0.00	28.57
Other acquaintances	37.51	18.86	2.20	26.74
Professionals	46.72	25.81	16.08	6.99

* Category (row) totals which differ from 100% reflect missing data (i.e. the participant could not indicate a main initiator of contact).

2.3.2 Functional characteristics of the social networks

With respect to the functional characteristics of the social networks of the participants in our study, Table 4 shows the mean scores along a five-point scale for affection, connection, preference and practical/informational support.

The differences in the functional characteristics of the social networks across groups were analyzed in two ways. First, we analyzed the differences for each separate function across the three main groups: family, acquaintances and professionals. There were significant main effects on practical/informational support and on connection, $F(2,50) = 6.293$, $p = .004$ and $F(1.23, 29.61) = 10.017$, $p = .002$, respectively. With respect to practical/informational support, higher scores were found for professionals compared to both family and acquaintances – significant ($p = .001$) and nearly significant ($p = .058$) differences. With respect to connection, significantly higher scores were found for acquaintances compared to both family ($p = .001$), and professionals ($p = .005$). No significant differences between the scores of the groups on either affection or preferences were found.

The second way in which we examined the functional characteristics of the social networks was to analyze the characteristics *within* each group of network members (i.e. the family, acquaintances and professionals) for significant differences. Significant differences between the scores on functional characteristics were found for all three groups: for family, $F(2.44, 75.50) = 31.726$, $p < .001$; for acquaintances $F(1.94, 54.28) = 6.322$, $p = .004$; and for professionals $F(2.01, 58.36) = 44.486$, $p < .001$. Post hoc comparisons revealed significantly lower scores on the connection characteristics than on all of the other functional characteristics for each group ($p < .01$ for all tests); one exception was the difference between connection and practical/informational support for the group of acquaintances alone, which was not significant. The only other significant differences between the functional characteristics within a group were as follows: (a) within the family, significantly higher scores on preference and affection compared to practical/informational support ($p = .018$ and $p = .037$, respectively); (b) within professionals higher score on practical/informational support compared to preference, $p = .008$. In sum, the participants judged the extent to which network members meet their need for connection relatively low, particularly when compared to the meeting of their other needs.

Table 4 *Functional characteristics of the social network: Means along a five-point scale (SD)*

	Affection	Connection	Preference	Practical/ Informational Support
Family	3.93 (0.7)	2.91 (0.8)	4.09 (0.6)	3.63 (0.8)
Partner/children	4.47 (0.6)	3.21 (1.2)	4.65 (0.8)	4.18 (1.2)
Parents	4.33 (0.7)	3.00 (1.1)	4.37 (0.8)	4.02 (1.2)
Brothers/Sisters	3.61 (1.3)	2.64 (1.1)	3.93 (1.1)	3.46 (1.5)
Other Family	3.64 (1.1)	2.71 (1.0)	3.80 (0.9)	3.49 (1.3)
Acquaintances	3.80 (0.6)	3.32 (0.8)	4.00 (0.6)	3.75 (1.0)
Friends	3.69 (0.7)	3.33 (0.8)	3.96 (0.8)	3.76 (1.0)
Colleagues	4.14 (0.7)	3.23 (1.0)	4.11 (0.6)	4.02 (1.2)
Neighbours	4.29 (1.0)	3.93 (0.9)	4.43 (0.8)	3.71 (1.5)
Other acquaintances	3.10 (1.1)	2.81 (1.3)	3.80 (1.1)	3.61 (1.0)
Professionals	4.00 (0.8)	2.35 (1.1)	3.90 (0.8)	4.30 (0.8)

2.4 Discussion

In this study, we investigated the structural and functional characteristics of the social networks of people with mild ID from their own perspective. Several findings are noteworthy in relation to the existing literature and for their practical implications. First, the results with regard to the size of the social networks are in line with the results of previous research on the social networks of individuals with ID although the size in the research literature varies from a median of six network members (Robertson et al., 2001) to an average of 11.67 (Lippold & Burns, 2009) and 22 (Forrester-Jones et al., 2006) for people with ID in community-based residences. Differences across studies in the size of the social networks of people with ID may also be attributable to the use of different instruments: the MSNA (Baars, 1994), which was used in the present research; the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994); the Social Network Guide (Forrester-Jones et al., 2006); or the Social Support Self Report (Lippold & Burns, 2009). Similarly, interviewing the participants themselves (Forrester-Jones et al., 2006; Lippold & Burns, 2009) versus proxy informants like support staff (Robertson et al., 2001) could contribute to the observed variation in the size of the social networks reported across studies. In the present study, the individuals with the mild ID served as the informants as they are the experts on their feelings, experiences and thus on their own opinions (Cambridge & Forrester-Jones, 2003; Forrester-Jones et al., 2006); research has also shown people with mild ID to be reliable reporters of social support (Lunsky & Benson, 1997).

A second noteworthy finding is that although the participants were living independently in the community for more than two years, approximately a quarter of their social network consisted of professionals (e.g. support staff). These professionals are highly appreciated by individuals with mild ID, as indicated by the scores produced on the functional characteristics of affection, preference (comparable with family/acquaintances) and practical/informational support (significantly higher when compared to family and almost significantly higher when compared to acquaintances). Professionals thus play an important role in the social networks of people with mild ID living in the community. Staff members can be seen to be key agents in a wide range of areas including the attainment of social inclusion goals for people with ID (McConkey & Collins, 2010) and behavioural interventions for people with ID and challenging behaviour problems (Felce, Lowe, Beecham, & Hallam, 2000). In recent research, however, support staff have indicated that they may be *too* important for clients living in a community (van Asselt-Goverts et al., 2014). This finding is in line with other research showing support staff to be the *main* providers of both emotional and practical support (Forrester-Jones et al., 2006). This situation can perhaps be explained by – on the one hand – so-called learned dependence which refers to the predisposition of individuals to rely on others when they do not know what to do rather than trying to help themselves and – on the other hand – the predisposition of professionals to act on the behalf of people with ID rather than help them learn to do things themselves (van Gennep, 1994). Support staff must thus recognize their importance and, when it is decided to reduce their support, clearly discuss this with the client so that he or she can work on meeting his or her needs for affection, connection, and practical/informational support via their informal network (i.e. family, friends, colleagues, neighbours and other acquaintances).

Several findings are noteworthy with respect to the other structural characteristics we examined: (a) the participants had a high frequency of contact with family and acquaintances; (b) the participants with ID considered themselves more often the main initiator of contact than the other members of their social networks; (c) only seven of the 33 participants mentioned neighbours on the MSNA and the neighbours who were mentioned were often reported as also having an ID and highly valued with respect to various functional characteristics; and finally (d) involvement in work or school appeared to be an important way of making friends. In professional practice, it is thus important that these findings be taken into account. In such a manner, interventions can be tailored to the strengths and weaknesses of the individual's social network. Professionals should, for example (a) avoid overburdening the social network (Oudijk, de Boer, Woittiez, Timmermans, & de Klerk, 2010) and therefore adopt interventions aimed at expanding and improving the individual's social network (van Asselt-Goverts et al., 2014) rather than simply increasing the frequency of contact; (b) investigate the reasons for a client being the main initiator of contact or perceiving him/herself to be the main initiator of contact; (c) stimulate client contact with neighbours, including neighbours without ID (van Alphen, Dijker, van den Borne, & Curfs, 2010); and (d) stimulate clients to make new acquaintances and friends via participation in the community, employment, school, the neighbourhood, clubs, the internet and going out (van Asselt-Goverts et al., 2014; McConkey & Collins, 2010).

A fourth noteworthy finding is that the meeting of the need for connection on the part of the participants in our study was perceived to be low, particularly with respect to the other functional characteristics we examined. People with mild ID have – just as other people – this need to belong, find support and connect with others on the basis of shared interests, values and backgrounds (Baars, 1994). To promote such a connection, it is therefore recommended that greater attention be paid to the interests of a client and greater effort be expended to bring people with similar interests together (van Asselt-Goverts et al., 2014; Lunsky, 2006).

At this point, some possible limitations on the present study should be mentioned. First, the focus of our study was on young adults with mild ID living independently. This means that the present results cannot be generalized to other target groups like older clients, clients with a different degree of ID or clients living in a different type of accommodation. Second, psychometric data on the reliability and validity of using the MSNA with people with ID are still lacking. Nevertheless, the MSNA has been used with different research populations, including people with psychiatric problems (Baars, 1994), fibromyalgia patients (Bolwijn, van Santen-Hoeufft, Baars, Kaplan, & van der Linden, 1996) and Kenyan street children (Ayuku, Kaplan, Baars, & de Vries, 2004). In the present study, the MSNA also appeared to be a useful instrument for systematically mapping the social networks of people with mild ID. Compared to some other instruments (e.g. the Social Network Map, Robertson et al., 2001) the adapted form of the MSNA which we used gives a large amount of information on both the structural and functional characteristics of the social networks. Our participants were able to answer the questions, and it thus appears that the adapted form of the MSNA used here can also be used for diagnostic purposes with people with mild ID. A third possible limitation on the present study is that the status of the members of a social network as also having an ID should be interpreted with caution. This information is based on the participant's knowledge/perceptions but it is uncertain whether such a question can be accurately answered by this target group or whether the participants can adequately judge the intellectual level of other network members. We tried to determine the educational levels of network members, but the participants in our study could not answer this question for 61.89% of family relationships and 65.14% of acquaintances. Several other studies have nevertheless shown the social networks of people with ID to typically include very little contact with people who do not have ID (i.e. contact with only families and caregivers who do not have ID) (Dusseljee et al., 2011; Lippold & Burns, 2009; Verdonschot et al., 2009).

In future research, attention should also be paid to the social networks of individuals with moderate and severe ID as these people are rarely considered in the participation literature (Verdonschot et al., 2009). Reciprocity is also recommended as a topic for future research. In the present research, we examined the reciprocity of the initiation of contact, but the reciprocity of support should also be considered in the future as reciprocity is a key factor for the maintenance of supportive relationships over time (Biegel, Tracy, & Corvo, 1994; Ferlander, 2007; Lunsky, 2006). Furthermore, the individual's satisfaction and wishes with respect to the social network should be explored in future research. With this information, interventions can be tailored to not only the strengths and weaknesses of an individual's social network but also to the actual opinions and desires of the individual with a mild ID. Finally, future research should include matched norm groups for comparison purposes (i.e. groups matched according to age and sex but without ID). Do the scores of people without ID actually differ from the scores of people with ID for the various structural and functional characteristics of their social networks? And if so, how do they differ? Comparison with a norm group can also facilitate the interpretation of the data found in the present study and other studies on the social networks of people with ID by providing information on the average size and composition of the social network, frequency of contact with network members, nature of the initiation of contact within the network and functional characteristics of the social network.

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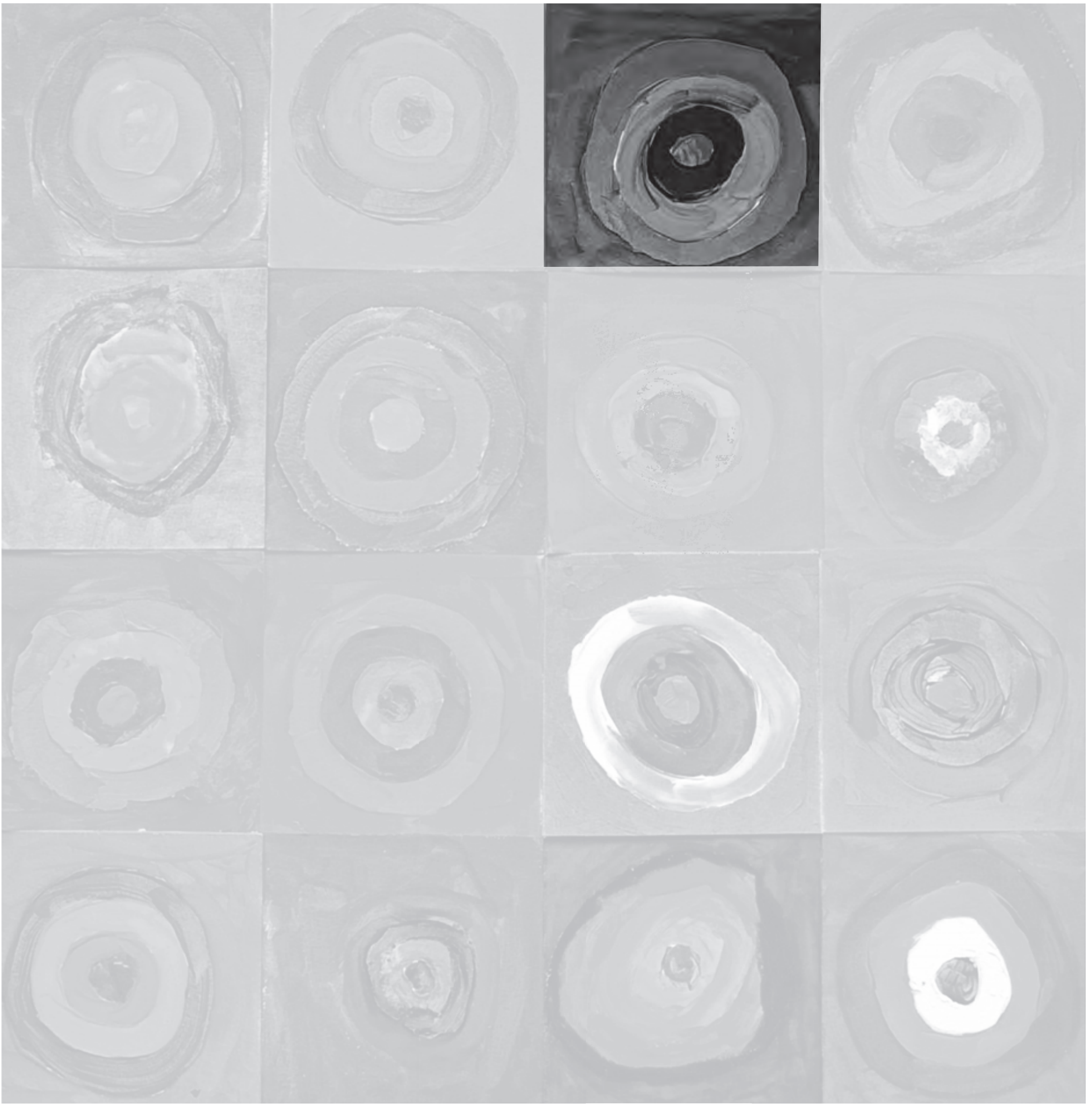

Chapter 3

Social networks of people with mild intellectual disabilities: characteristics, satisfaction, wishes and quality of life

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Abstract

Background A supportive social network is crucial for facilitating social inclusion, which can, in turn, contribute to the quality of life (QOL) for people with intellectual disabilities (ID). In this study, we investigate how people with mild ID perceive their social networks and which network characteristics relate to satisfaction with the network and perceived QOL.

Method Data were gathered from 33 young adults with a mild to borderline ID using structured questionnaires: the MSNA to map the social network, the IDQOL-16 to assess QOL, and a questionnaire to determine satisfaction and wishes with regard to the social network.

Results The majority of the participants (73.1%) were satisfied with their social networks. Improvement in the area of strengthening existing ties (e.g. more frequent contact, better contact) was desired as opposed to expansion of the network. Affection – especially towards family and professionals – was most strongly related to perceived QOL. It appears to be essential that relatives live in the same town, can frequently meet up and provide both emotional and practical support.

Conclusions The significance of family and the importance of high-quality interpersonal relationships between professional and client in the lives of young adults with ID cannot be overestimated. Although measures of satisfaction and wishes can have limitations, in actual practice it is considered useful to assess the opinions of clients with respect to their social networks. Interventions can then be tailored to the needs and wishes of the persons themselves.

3.1 Introduction

Attention to the social networks of people with intellectual disabilities (ID) has increased in recent decades. This has been under the influence of the quality of life (QOL) concept, which encompasses interpersonal relations in addition to personal development, self-determination, rights, participation and emotional, physical and material well-being (Verdugo, Navas, Gómez, & Schalock, 2012). QOL is increasingly being used to measure the well-being of the person in both practice and research. QOL has both subjective and objective components (e.g. Cummins, 2005; Nota, Soresi, & Perry, 2006; Verdugo et al., 2012). Objective components represent externally manifested items such as income; subjective components consist of the perception of a person's life in general or of specific aspects of it (Miller & Chan, 2008). In QOL research structured questionnaires are used, yielding standardized results, but also more general measures on subjective well-being (SWB; i.e. satisfaction with life as a whole) (Cummins, 1995, 2005; Miller & Chan, 2008). SWB can be measured asking '*How do you feel about your life in general?*' (Andrews & Withey, 1976 in Cummins, 1995). This global assessment of QOL is not framed by any objective conditions or ideas of the interviewer what might be important factors; instead it refers to all aspects of life relevant to the respondent (Barrington-Leigh, 2009).

The indicators used in QOL research differ, but indicators of the quality of interpersonal relations and social inclusion are most often referred to (Schalock, 2004). One of the indicators of the quality of interpersonal relations is the social network of the person (Verdugo et al., 2012). This network can be understood from two perspectives: a structural one (e.g. in terms of size and frequency) and a functional one (e.g. in terms of perceived emotional and practical support) (Lunsky, 2006). In investigations of people with ID, attention is paid to both the structural and functional characteristics (e.g. Forrester-Jones et al., 2006; Robertson et al., 2001; van Asselt-Goverts, Embregts, & Hendriks, 2013). With respect to structural characteristics, research shows that the social networks of people with ID are often small and that the only contact with people *without* ID is family and/or professionals (e.g. Lippold & Burns, 2009; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). People with ID have also recently been shown to have a high frequency of contact with their network members (van Asselt-Goverts et al., 2013). For instance, they saw their parents and friends almost twice a week; siblings, other acquaintances and professionals about once a week; and colleagues and neighbours three to four times a week. Moreover they had frequent telephone contact with parents (three times a week) and friends (two times a week). With respect to functional characteristics, research indicates that social support is perceived as mainly coming from professionals (Forrester-Jones et al., 2006). People with ID look just as much to professionals for affection as to family and acquaintances but, for practical/informational support, professionals are valued even higher than family and acquaintances (van Asselt-Goverts et al., 2013). Little attention, however, has been paid to the *satisfaction* of people with ID with either the structural or functional characteristics of their social networks or their wishes with regard to such (e.g. Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; van Asselt-Goverts et al., 2013).

With respect to the relations between the characteristics of the social networks of people with ID, on the one hand, and their satisfaction with their network and perceived QOL, on the other hand, some studies have documented associations between network size and satisfaction with the social network, QOL, SWB or feelings of loneliness (Campo, Sharpton, Thompson, & Sexton, 1997; Duvdevany & Arar, 2004; Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001; Stenfert Kroese, Hussein, Clifford, & Ahmed, 2002). Moreover better SWB or QOL was found to be associated with more frequent contact with friends (Cram & Nieboer, 2012; Emerson & Hatton, 2008), but not with family (Emerson & Hatton, 2008). Also an association of life satisfaction/subjective QOL with perceived social support has been found (Bramston, Chipuer, & Pretty, 2005; Lunsky & Benson, 2001; Miller & Chan, 2008). However, in some of the referred studies, social network components have been measured using just one question or a few questions (e.g. Cram & Nieboer, 2012; Emerson & Hatton, 2008).

Overall, to the best of our knowledge no attention has been paid in research on the social networks of people with ID to their specific needs or wishes with respect to such. Therefore the first aim of this study was to investigate the degree of satisfaction and any wishes on the part of people with mild ID for their social networks. The structural and functional characteristics of the social networks of people with ID have been shown to be related to their satisfaction with the social network and perceived QOL in the following manner. There is some evidence of an association of network size, frequency of contact and perceived support with SWB, satisfaction with the social network or QOL. However, research on social networks and SWB from the perspective of the persons with ID themselves is sparse (Emerson & Hatton, 2008) and systematic investigation of the characteristics of their social networks in relation to their perceived QOL is lacking. A second aim of this study was therefore to examine the social networks of people with ID more thoroughly in relation to their satisfaction with the networks and perceived QOL, by considering both the structural and functional characteristics of the social networks and distinguishing specific groups of people in the network (i.e. family, acquaintances, professionals). In doing this, we posed the following research questions:

1. How satisfied are young adults with mild ID with their social networks?
2. What are the wishes of young adults with mild ID with respect to their social networks?
3. Is there a relation between the structural and functional characteristics of the social networks of young adults with mild ID, on the one hand, and their satisfaction with the social network and perceived QOL, on the other hand?

3.2 Method

3.2.1 Participants

Clients from seven care organizations, located in the south-east of the Netherlands, participated in this research. All organizations provided both residential and ambulant support for people with ID. Participants had to meet the following inclusion criteria: (a) a mild to borderline ID; (b) age between 19 and 36 years; and (c) independent residence in the community for at least 2 years (i.e. with partner, friend, children or alone). Persons with ID but living in a residential facility were thus excluded from the present study, which started with an accidental sample of 38 participants. To obtain a sufficient large sample, all persons who met the inclusion criteria and who were willing to participate in the study were approached. One person could not be reached; another cancelled the appointment and another three participants could not be included in the analyses in the end because of incomplete data. A total of 33 participants, who all provided written informed consent, participated in this study; 16 men and 17 women. The number of participants per care organization varied from two to seven. All participants received support from staff from the care organization; many of them got job coaching as well and some participants were consulting a specialist, such as a psychiatrist. The average age of the participants was 28.88 years. Approximately half of the participants had a partner (n = 17), but not all lived together with the partner. Most of the participants were living alone (n = 23); others were living with their partners (n = 7) and/or children (n = 3). With regard to employment and work outside the house: 78.79% of the participants were employed or had activities outside the home during the day; the remaining 21.21% were either unemployed, unable to work and/or responsible for the housekeeping at home. The social networks of the participants varied from four to 28 members (M = 14.21). Almost half of the network members were family members (42.65%) and 32.84% of the network members were acquaintances (i.e. friends, colleagues, neighbours and other acquaintances). The remaining 24.51% of the network members were professionals. The number of informal (not paid) network members ranged from two to 24 (M = 11.21). One of the 33 participants in this study had no family members; four had no acquaintances in their networks whatsoever. A more detailed description of the social networks, including details of their size, has been previously reported (van Asselt-Goverts et al., 2013).

3.2.2 Measures

Maastricht Social Network Analysis

The structural and functional characteristics of the social networks of the participants in this study were mapped using the Maastricht Social Network Analysis (MSNA) (Baars, 1994). Important network members are listed to get started and can include: family (i.e. partner, children, parents, brothers/ sisters and other family members); acquaintances (i.e. friends, colleagues, neighbours and other acquaintances) and professionals (e.g. support staff, therapists, social workers, coaches). A number of structural characteristics (e.g. accessibility, length of the relationship, frequency of contact) are then scored for each member of the network. Each relationship is also then scored using a five-point scale for a number of functional characteristics – namely the supportiveness of the contact operationalized along four dimensions: affection (e.g. feeling safe and secure with the person, loving the person), connection (e.g. liking the same things), preference (e.g. preference for contact with the person, liking the contact) and practical/informational support (e.g. being helped by the person when you don’t know something or aren’t able to do something).

To ensure a minimum of reliability and validity for the MSNA, the following were taken as starting points: (a) only information on network members with whom there is a direct connection should be provided; (b) the information obtained in such a manner is of a largely objective, factual nature; and (c) only information which is known for certain is provided with anything which is uncertain thus omitted (Baars 1994).

For the present study, the original form of the MSNA was adapted for use with people with mild ID by simplifying the questions and using visualization. First, a genogram (i.e. family tree) was used to map the characteristics of the participant's family relations. Second, an ecogram was created to visualize the remainder of the social network. Three expanding circles are placed around the name of the participant who then maps his or her relations with friends, neighbours, colleagues, other acquaintances and professionals by pointing to where a particular network member should be placed. The more important the network member, the closer the name is written to the name of the participant. Finally responses with respect to the functional characteristics of the participant's social network were provided along a five-point scale with the five response possibilities visualized as a stairway; the higher the score, the higher the step on the stairway.

Satisfaction and wishes with regard to the social network

To assess the satisfaction and wishes of the study participants with regard to their social networks, we developed a questionnaire which consisted of questions about the network in general ('*How satisfied are you with your social network?*') and questions about the family, acquaintances and professionals in the network in particular ('*How satisfied are you with your network of family/ acquaintances/professionals?*'). Responses were provided along a five-point scale with the five response possibilities visualized as a stairway as described elsewhere in this article. The participant was then asked: *'What would make your network one step higher?'*. These so-called 'scaling questions' have their roots in Solution Focused interviewing (de Jong & Berg, 2008) and gave us insight into the wishes of the participants with regard to their social networks.

Intellectual Disability Quality of Life-16

Quality of life was measured using the Intellectual Disability Quality of Life-16 (IDQOL-16) which consists of 16 questions which address psychological well-being, social well-being and housing satisfaction (Hoekman, Douma, Kersten, Schuurman, & Koopman, 2001). Five response categories ranging from very dissatisfied to very satisfied are available and made clear using emoticons (i.e. smileys). Higher scores reflect a higher QOL.

For purposes of the present study, a minor change was made: the smiley response possibilities were positioned along a 'stairway' just as for the other instruments. This was done in order to facilitate comprehension but also establish some uniformity across the measurement instruments. The internal consistency of the IDQOL-16 in previous studies has been found to vary from .85 for adults with ID (Hoekman et al., 2001) to .83/.84 for proxies of children with ID (Cram & Nieboer, 2012) and .74 for adults over 50 years of age with moderate to mild ID (van Puyenbroeck & Maes, 2009). The internal consistency of the IDQOL-16 in the present study was .74.

3.2.3 Procedure

The scientific and ethics committee from *Dichterbij*, one of the seven organizations participating in this research, approved the present study. The support staff from the organizations participating in the study were next asked to invite clients who met the inclusion criteria to take part. In total 33 clients agreed to participate and provided written consent. Interviews were next conducted by trained undergraduates at the HAN University of Applied Sciences in the Netherlands.

At the start of each interview, the participant was informed about the aims of the study that all responses would be handled without name and that it was possible to stop the interview at any point. To enhance the reliability of data collection, we used an interview protocol and accompanying instruction manual (van Asselt-Goverts et al., 2012). The interviewers were trained on the use of the protocol and how to conduct an interview. All of the interviews were voice recorded, and the responses of the participants were also noted during the interviews.

3.2.4 Data analysis

The data were processed and analyzed using SPSS. To map the social networks of the participants, both the total network and different groups within the network were analyzed: family (i.e. partner, children, parents, brothers/sisters and other family members); acquaintances (i.e. friends, colleagues, neighbours and other acquaintances) and professionals. Network members were included in the analyses when they were over the age of 12 years. With respect to wishes, the first expressed wish was coded and subcategorized further. Decisions concerning the coding and sub-categorization of the wishes were discussed among the three researchers in the research group.

In the analyses several steps were undertaken. First, we determined the satisfaction of people with ID with their current social networks and their wishes with regard to such. Percentages were calculated for this purpose. Second, we examined the associations between characteristics of the social network, on the one hand, and satisfaction with the social network and perceived QOL, on the other hand. We calculated mean scores with regard to the following for this purpose: (a) structural characteristics, namely size of the social network, frequency of contact, length of the relationships, accessibility of network members (mean % living in same town); (b) functional characteristics (i.e. affection, connection, preference and practical/informational support); and (c) satisfaction with the social network and QOL. Satisfaction with the social network was calculated as the mean of the items for satisfaction with family, satisfaction with acquaintances and satisfaction with professionals. Third, Pearson correlations were calculated for the structural and functional characteristics of the social network, on the one hand, with satisfaction and QOL, on the other hand. To limit the number of statistical tests, scores for the *total network* were analyzed first. If the Pearson correlation for one of the characteristics of the social network characteristics with either satisfaction or QOL proved significant, then additional correlations were calculated to determine *which group of network members* was of primary importance (i.e. family, acquaintances or professionals).

3.3 Results

In the following, the satisfaction and wishes of the 33 participants with regard to their social networks will first be summarized. Thereafter, the associations between, on the one hand, the structural and functional characteristics of the social networks and, on the other hand, their satisfaction with the social networks and perceived QOL will be presented.

3.3.1 Satisfaction and wishes with respect to social networks

In Table 1, the degrees of satisfaction of the participants with respect to their social networks in general, but also to family members, acquaintances and professionals in their social networks in particular, are presented. Scores of 1 and 2 from the five-point scale were summed as indicators of 'dissatisfied'. Scores of 4 and 5 from the five-point scale were summed as indicators of 'satisfied'. Of the 33 participants in the present study, 73.1% responded that they were satisfied with their social network; 26.9% responded that they were neutral or dissatisfied.

Table 1 *Satisfaction with the social network (%)*

	Dissatisfied	Neutral	Satisfied
Network total (*n* = 26)	3.8	23.1	73.1
Family (*n* = 28)	7.1	25.0	67.9
Acquaintances (*n* = 27)	7.4	14.8	77.7
Professionals (*n* = 27)	11.1	7.4	81.5

In Table 2, the wishes of the participants with regard to their social networks are summarized. The wishes were indicated in response to the open-ended question *'What would make your network one step higher?'*, which was asked with regard to the total social network, family, acquaintances and professionals. With regard to the total network, a desire for better contact was most often indicated (25.0% of the participants). This category refers to having similar interests, wanting nicer contact and or being taken more seriously. According to one participant:

> *I wish I could trust people more. I am buggered around very often. So I don't really trust people. ... They should not promise things, if they are not able to keep their promises.*

Of the participants, 16.7% indicated a wish with regard to social skills (e.g. learn to take more initiative, learn how to deal with others, learn how to enter more easily into new contacts) and 12.5% indicated that they would like more frequent contact with members of their network. One participant said:

> *I wish I had more often contact with my godfather. ... It is a pity to see him only on birthdays.*

Only one participant wished to expand his/her network by meeting new people. A large number of the participants reported having no specific wishes. Either they were already satisfied (20.8%) or they could not come up with something during the interview, found the question too difficult to answer or thought that real change was not possible (12.5%). In the words of one participant:

> *It is not possible to put my network a step ahead. It is as it is.*

No response was noted for nine of the participants. When the wishes of the participants are examined with regard to family, acquaintances and professionals, it is remarkable that they would like more frequent contact with their family (35.7%) compared with acquaintances (16.0%) and professionals (16.7%). They would like to have better contact with acquaintances (32.0%) and professionals (25.0%). And they would like to improve their social skills with acquaintances (20.0%).

Table 2 *Wishes with respect to social networks (%)*

Wishes	Total network (*n* = 24)	Family network (*n* = 28)	Acquaintances network (*n* = 25)	Professionals network (*n* = 24)
More frequent contact	12.5	35.7	16.0	16.7
Better contact	25.0	10.7	32.0	25.0
Expanded network	4.2	3.6	0.0	4.2
Improved social skills	16.7	7.1	20.0	0.0
No wish	33.3	28.6	28.0	37.5
Other wishes	8.3	14.3	4.0	16.7

3.3.2 Correlations between characteristics of social network and satisfaction/QOL

The scores for the structural characteristics of the social networks (i.e. size, frequency of contacts, length of contacts and accessibility of contacts) and the functional characteristics of the social networks (i.e. affection, connection, preference and practical/informational support) have been previously reported in detail (van Asselt-Goverts et al., 2013). The mean satisfaction score for the questions regarding contact with the family, acquaintances and professionals in the social network was 4.05 (*SD* 0.9) on a scale of five. The mean QOL score was 3.65 (*SD* 0.6) on a scale of five. Both scores were above the mid-point of the scale, which suggests that the participants were quite satisfied with their social networks and their lives. The association between satisfaction with the social network and perceived QOL was significant, $r = .398$, $p = .036$.

Table 3 shows the correlations between characteristics of the social network, on the one hand, and satisfaction with the social network and perceived QOL, on the other hand. Analysis of the associations between characteristics of the social networks and participants' satisfaction with their social networks revealed satisfaction to be significantly ($p < .05$) related to three structural characteristics: the number of network members, the frequency of telephone contact and the accessibility of network members. The larger the social network, the more telephone contact and the greater the accessibility (because of network members living in the same town), the more satisfied participants reported being with their social network. When the Pearson correlations were calculated to further explore the relations for the different groups within the social networks (i.e. family, acquaintances and professionals), two characteristics of the social networks stood out in particular. The number of acquaintances (i.e. friends, colleagues, neighbours, other acquaintances) correlated significantly with the participant's satisfaction with the network, $r = .448$, $p = .017$. And the proportion of family members living in the same place correlated significantly with satisfaction, $r = .389$, $p = .045$. The other correlations with the size of the network, telephone contact and accessibility of particular groups within the network were not significant for satisfaction.

Table 3 *Pearson correlations for characteristics of social networks with satisfaction and QOL*

	Satisfaction		QOL	
	r	*p*	*r*	*p*
Structural characteristics				
Size	.428*	.023	.131	.466
Frequency Face-to-Face	.100	.613	.348*	.047
Frequency Telephone	.380*	.046	-.083	.645
Frequency Internet	.257	.214	-.245	.192
Length[a]	.138	.484	-.049	.787
Accessibility[b]	.410*	.030	.217	.225
Functional characteristics				
Affection	.152	.441	.576***	.000
Connection	.065	.741	.320	.070
Preference	.301	.120	.460**	.007
Practical/Informational support	-.100	.611	.355*	.043

[a] Only for acquaintances and professionals; [b] Only for family and acquaintances;
*$p < .05$; ** $p < .01$; *** $p < .001$.

Analysis of the characteristics of the social networks in relation to the participants' perceived QOL showed affection to be the most strong predictor ($p < .001$). Further exploration revealed that QOL was specifically related with affection assigned to family and professionals, respectively, $r = .493$, $p = .004$ and $r = .624$, $p < .001$. In addition, the analysis of the associations between the characteristics of the participants' social networks and their perceived QOL showed both preference and practical/informational support to be also significantly related to QOL ($p < .05$). When the participants had a higher preference for contact with family and professionals in the social network, their reported QOL was also higher ($r = .390$, $p = .027$ and $r = .437$, $p = .014$ respectively). Practical and informational support from family members was also important for perceived QOL, $r = .510$, $p = .003$. Finally, the frequency of face-to-face contact (i.e. a structural characteristic of the social network) was significantly associated with perceived QOL, particularly for family members, $r = .388$, $p = .028$. The more frequent face-to-face contact, the more positive the participants perceived their QOL.

3.4 Discussion

In this study, we investigated the satisfaction of persons with mild ID with their social networks and their wishes with regard to such. We then investigated the relation of their satisfaction and reported QOL to the specific structural and functional characteristics of their social networks.

The vast majority of the participants in our study (73.1%) were *satisfied* with their social networks. This finding is in line with the results of previous research showing high percentages of adults with ID to have mildly positive to very positive levels of satisfaction with their friendships and relationships (68%) and support received (81%) (Gregory et al., 2001). Cummins (1995) found that life-satisfaction/SWB scores are 75 ± 2.7% of the Scale Maximum (SM) for both individuals with as without ID[1]. This can be explained by psychological, homeostatic mechanisms that maintain the average level of life satisfaction on a certain level (Cummins, 1995, 2005). Under relatively stable but diverse living conditions, most people feel satisfied with their lives (Cummins, 1995). The mean satisfaction score in the present study, 76.3% SM, is in line with this finding; the mean QOL score, 66.3% SM, is below this standard score.

With regard to the *wishes* expressed by the participants in connection with their social networks, only one indicated a need or desire to expand the network. The participants mentioned, rather, a desire to strengthen existing ties and in particular: (a) better contact, especially with acquaintances and professionals; (b) better social skills, specifically in contact with acquaintances; and (c) more frequent contact, especially with family. However, in previous research (van Asselt-Goverts et al., 2013), it was found that these same participants already had a high frequency of contact with relatives (e.g. twice a week with parents, once a week with siblings and every other week with other family).

The participants' *perceived QOL* related most to the functional characteristics of their social networks, which is in line with the findings of previous research showing an association between perceived support and subjective QOL (Bramston et al., 2005; Lunsky & Benson, 2001; Miller & Chan, 2008; Stenfert Kroese et al., 2002). Our results provide more detailed insight into the perceived support and show *affection* to relate most strongly to perceived QOL. Specifically, affection assigned to family and professionals is of special importance to young adults with mild ID. Our previous research also showed

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[1] The % SM is defined by Cummins (1995) as: (score − 1) × 100/(number of scale points − 1).

professionals to be highly *valued* by people with mild ID with respect to several functional characteristics (van Asselt-Goverts et al., 2013). The present research adds to these findings by showing the quality of the contact with professionals to be of great importance for the overall well-being of the client with ID. High-quality interpersonal relations between professional and client are part of so-called professional loving care (Hermsen, Embregts, Hendriks, & Frielink, 2014).

With respect to size the number of *acquaintances* (i.e. friends, colleagues, neighbours and other acquaintances) appears to be of importance for a person's satisfaction. For other characteristics, however, the *network of family members* seems crucial. For young adults with mild ID, it appears to be essential that relatives live in the same town and provide both emotional and practical support. Moreover, contrary to the finding of Emerson & Hatton (2008) mentioned in the Introduction, in the present study frequency of face to face contact with *family* is significantly related to the perceived QOL.

There are some potential limitations to the present study. We collected data on the social networks and QOL from the perspective of the people with mild ID living independently. This was done to shed light on their actual perspectives, but the participants in our study are not necessarily representative of the entire population of people with ID. In QOL research into people with ID, moreover, the question arises of whether they are able to reliably evaluate their own SWB or whether such information is better provided via proxies. Even though the conclusions of comparable studies are contradictory (Cummins, 2002; Nota et al., 2006; Schmidt et al., 2010; Verdugo, Schalock, Keith, & Stancliffe, 2005), the emerging consensus is that people with ID should be asked to give their own views (Roeleveld, Embregts, Hendriks, & van den Bogaard, 2011; Verdugo et al., 2005). Proxies should only be used in place of the subjects themselves as the sole source of information when absolutely necessary because of significant communication limitations (Verdugo et al., 2005). This was not the case in this study. In line with this view, we collected data on how participants perceived their actual network at the time of the interview. Although people with mild ID are regarded as reliable reporters of social support (Lunsky & Benson, 1997), the information may be affected by difficulties in giving an accurate account of the facts, such as difficulty in recalling the frequency of contact with network members. Gathering additional data from proxies is therefore recommended for future studies, particularly when it involves people living in group homes. For people living on their own in the community acquiring additional data with, for example, video diaries is a possibility. Video diaries can be a rich source of information and insight and provide another means for the participants to express their views (Jahoda, Wilson, Stalker, & Cairney, 2010; Stalker, Jahoda, Wilson, & Cairney, 2011). An approach using multiple sources of information is considered to provide the most accurate and comprehensive picture of social inclusion (Amado, Stancliffe, McCarron, & McCallion, 2013).

Moreover, the self-report measures used in this study may be prone to a social desirability bias. Socially desirable responding is the tendency for participants to present a favourable image of themselves, either because the participants believe the information or because the participants 'fake good' to conform to socially acceptable values and avoid criticism (van de Mortel, 2008). We tried to reduce this bias by emphasising at the beginning of each interview: '*There are no good or bad answers, honest answers are always right*'. Moreover, the interviewers were instructed to avoid value judgements and suggestive questions. The reliability of self-reports of people with ID can be affected by their limited cognitive capacities as well as limited verbal comprehension (Taylor, 2002). We tried to reduce this by adapting certain measures, by simplifying the questions and by using visualization. Although we tried to ensure the questions were not too difficult, with respect to the satisfaction and wishes no answer was noted for respectively seven and nine participants. Of the participants who did answer the question on wishes one-third of them reported having no specific wishes. This might be an indication that, for some participants, these questions on satisfaction and wishes were too complicated to answer. Furthermore, the answers of those who did respond should be taken with some caution. Nota et al. (2006) stated that persons with mild ID can be satisfied, regardless of the negative conditions they experience. Thus, satisfaction measures may not reflect the person's actual circumstances and may mask the fact that the person has a limited social network. Just because someone reports being satisfied does not mean that they are socially connected. In this study reported informal networks varied from two to 24 members ($M = 11.21$). We recommend that future studies compare the characteristics of social networks, satisfaction with the social networks and remaining wishes with regard to their networks for people with and without ID. Comparative information should improve interpretation of the data. In addition, we recommend measuring not only satisfaction in future studies, but also making other types of assessment of the opinions of the subjects regarding their connectedness with others, such as loneliness questionnaires. Likewise, with respect to the wishes of the participants, a lack of knowledge or experience might be an explanation of the fact that participants did not mention the wish to expand their networks, even though their networks were not very large. People who do not have experience in making new friends may not be aware of the fact they could and may not even wish to have more friends.

We did not use multiple regression analyses in the present study to analyze the extent to which the structural and functional characteristics of the social networks were related to the satisfaction of people with ID with their social networks or their perceived QOL. Our sample size ($n = 33$) was too small in light of the number of predictor variables and some of the network characteristics were highly interrelated, which could introduce bias because of multicollinearity. Pearson correlations were calculated for the total network and then, where correlations were significant on $p = .05$ level, for specific groups within the network (i.e. family, acquaintances and professionals). The remaining number of tests still raised some concerns about the occurrence of type I errors (i.e. revealing false positive results). We did not choose using the Bonferonni correction, because in our relatively small sample size it would exacerbate the existing problem of low power (Nakagawa 2004) and it would increase the likelihood of type II errors (i.e. the occurrence of false negative results; Perneger, 1998). Instead the observed effect sizes (r) and the exact significance levels (p) were reported and thereby the focus was put on the strength of the relationships between variables (Nakagawa, 2004; Perneger, 1998). Conclusions with respect to the correlations with $p < .05$ should be taken with some caution. However, they do indicate many promising directions for future research highlighting which characteristics of the social network appear to be of major importance and therefore worthy of greater investigation. In future research, the use of larger sample sizes in order to be able to conduct multiple regression analyses and thereby unravel the observed interrelations is recommended.

Only the first wish expressed by the client in our study was coded. For future research, it is nevertheless recommended that more wishes be included and a more in-depth, qualitative approach to the analysis of the information provided be adopted. Moreover, future research should focus on the impact of relationship status (e.g. dating, cohabiting, married) and relationship happiness on SWB of people with ID, as in the general population a stable intimate relationship with a partner is a strong predictor of well-being (Dolan, Peasgood, & White, 2008), in particular a 'good marriage' (Gove, Hughes, & Briggs Style, 1983) or a 'happy relationship' (Kamp Dush & Amato, 2005). Also other factors which can contribute to SWB, such as employment (Dolan et al., 2008) should be investigated for people with ID. Finally, reciprocity (e.g. mutual feelings and mutual support) is also recommended as a topic for future studies because it is a key factor for the maintenance of supportive relationships over time (Biegel, Tracy, & Corvo, 1994; Ferlander, 2007; Lunsky, 2006).

A supportive social network is crucial for social inclusion. Support staff can enhance social inclusion (e.g. Abbott & McConkey, 2006) with interventions aimed at strengthening and expanding the social networks of clients (e.g. van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014). To tailor interventions to the strengths and weaknesses of the individual social network of a client, it is recommended that the social networks be systematically mapped using an instrument like the MSNA (Baars, 1994) but then adapted for use with people with ID (van Asselt-Goverts et al., 2012, 2013). Use of an instrument to measure satisfaction and wishes is also recommended. Only with the gathering of such information can interventions be tailored to the needs and wishes of the persons with ID themselves. In the present study, people with mild ID clearly expressed a wish to *strengthen* the existing ties in their social networks with – for example – more frequent and/or better contact. Expansion of the social network was not a major desire. This means that in addition to getting a client involved in leisure time activities and looking for volunteers to expand the client's social network, other interventions are needed to strengthen the *ties which already exist*. Support staff can be key agents in stimulating contact with the existing social network by stimulating the client to give someone in the network a call, call upon network members more frequently when help is needed and discuss any misunderstandings or problems which arise (van Asselt-Goverts et al., 2014). Of course the opinions and wishes of the clients themselves should guide the chosen intervention.

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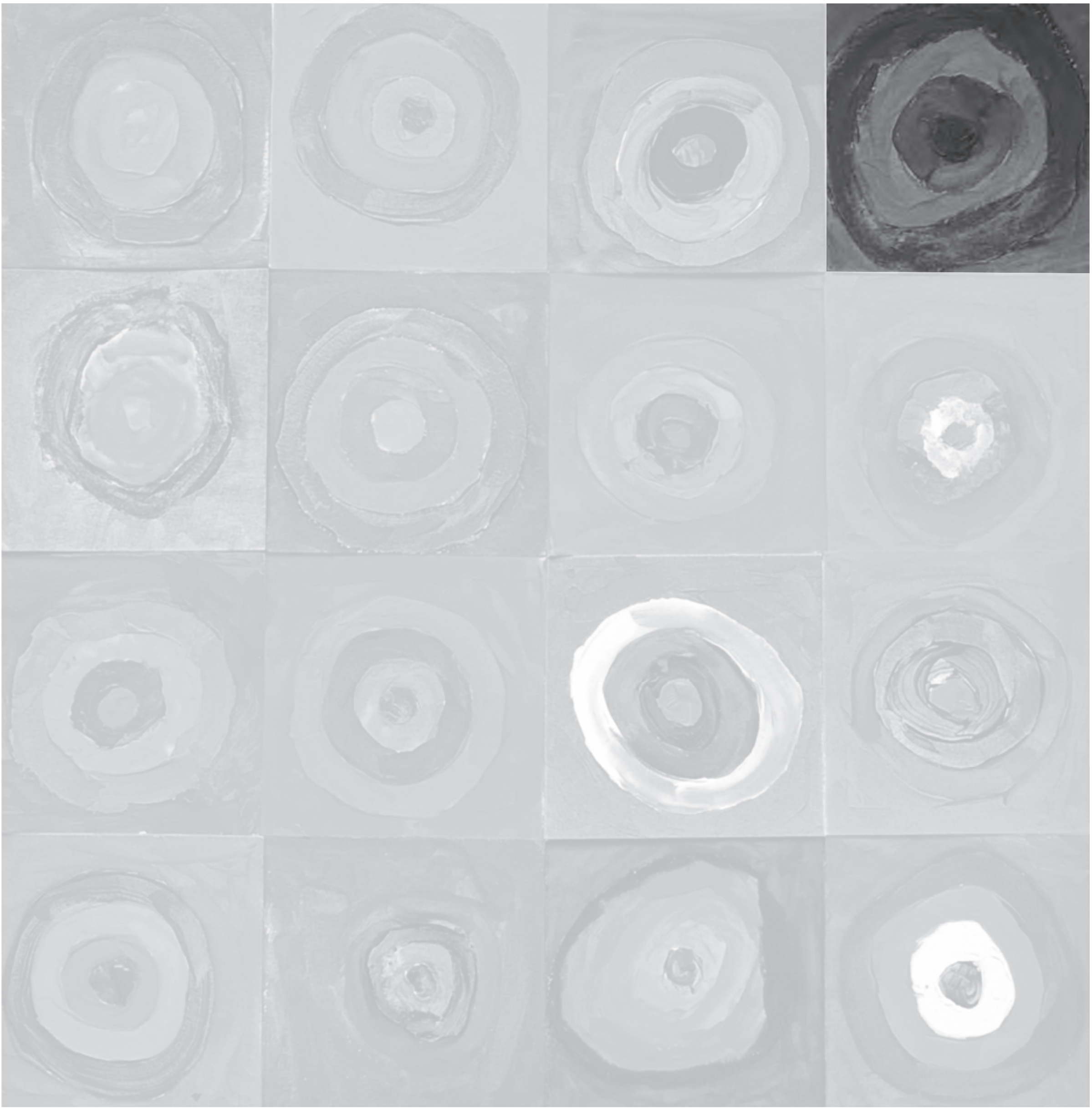

Chapter 4

Do social networks differ? Comparison of the social networks of people with intellectual disabilities, people with autism spectrum disorders and other people living in the community

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Abstract

The aim of this study was to determine the similarities and differences in social network characteristics, satisfaction and wishes with respect to the social network between people with mild or borderline intellectual disabilities (ID), people with autism spectrum disorders (ASD) and a reference group. Data were gathered from 105 young adults living independently in the community. The social networks of people with ID and ASD are more restricted than those of the reference group. Compared with the other groups, people with ASD are less often satisfied with their networks. Each group has its own characteristics, issues and wishes with respect to their social network. Practical measures to enable professionals to adapt to these issues are discussed.

4.1 Introduction

According to the United Nations Convention of the Rights of Persons with Disabilities, people with disabilities have the right to live in the community with choices equal to others (United Nations, 2006; Hewitt, Nord, Bogenschutz, & Reinke, 2013). This right is translated into policy worldwide, for instance in the United States in creating opportunities for community living (Hewitt et al., 2013) and in the United Kingdom, where people with disabilities are considered as citizens participating in all aspects of community and in control of the decisions in their lives (Department of Health, 2009). In the Netherlands —under the influence of the Dutch Social Support Act (Wet maatschappelijke ondersteuning, 2007)— more and more vulnerable people (e.g. elderly people or people with disabilities or disorders) are living independently in the community with the aim to participate in society (de Klerk, Gilsing, & Timmermans, 2010; Lub, Uyterlinde, & Schotanus, 2010). Physical presence in the community, however, does not guarantee real social inclusion, just as taking part in an activity does not guarantee meaningful social contact (Ager, Myers, Kerr, Myles, & Green, 2001). Real inclusion means supporting people to become connected, be part of the place or activity and belong (Gomez, 2013). Instead of moral imperatives of mainstreaming and independent living for all, meaningful activity and social relationships are needed to become someone instead of be placed somewhere (Clegg, Murphy, Almack, & Harvey, 2008). Research shows that professionals play an important role in facilitating social inclusion by mapping these social networks and supporting the person in expanding or strengthening his or her social network, if required (e.g. Abbott & McConkey, 2006; van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014). To achieve this, it is important to investigate the social networks of these vulnerable people living in the community. What are the characteristics of their social networks? How satisfied are they with their networks and what are their wishes with respect to them? In this article, we focus on two specific groups: high-functioning adults with autism spectrum disorders (ASD) and adults with mild intellectual disabilities (ID), because both these target groups experience difficulties in developing and maintaining social contacts. We compare the networks of these two groups with one another and with the networks of a reference group. Although people with ASD and ID both have limitations with respect to social contact, the nature and consequences of these limitations differ.

In the Diagnostic and Statistical Manual of Mental Disorders— Fifth Edition (DSM-5), autism spectrum disorder is characterized by two core symptoms: (a) deficit in social communication and social interaction and (b) restricted, repetitive behaviours, interests or activities (American Psychiatric Association, 2013). Three severity levels are defined, based on the amount of support needed due to these symptoms, which underlines the importance of social networks. Given the deficit in social communication and social interaction, people with ASD face significant difficulties in developing and maintaining contacts with network members (American Psychiatric Association, 2013; Friedman, Warfield, & Parish, 2013; Orsmond, Krauss, & Sletzer, 2004). However, research on social networks of adults with ASD is scarce (Orsmond et al., 2004). The existing research focuses mainly on the social networks of children (e.g. Bauminger et al., 2008; Bauminger & Kasari, 2000; Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011) and adolescents (e.g. Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Locke, Ishijima, Kasari, & London, 2010; Whitehouse, Durkin, Jaquet, & Ziatas, 2009), or on social support of the parents of children with ASD (e.g. Ekas, Lickenbrock, & Whitman, 2010; Siman-Tov & Kaniel, 2011; Weiss et al., 2013). Research shows that high-functioning children with autism report having at least one friend, but also that they are lonelier and have less complete understandings of loneliness compared to typically developing children (Bauminger & Kasari, 2000). These children perceive their friendships as less close, helpful and intimate (Bauminger et al., 2008). The majority of these children are at the periphery of their network at school and have poorer quality friendships and fewer reciprocal friendships (Kasari et al., 2011). Similar findings are reported for high-functioning adolescents with ASD: they feel lonelier (Lasgaard et al., 2010; Locke et al., 2010; Whitehouse et al., 2009), report poorer quality of their best-friendship (Whitehouse et al., 2009) and are socially isolated or at the periphery of their network at school (Friedman et al., 2013; Locke et al., 2010). Longitudinal research suggests some improvements of social behaviour when children with ASD reach adolescence and adulthood (Seltzer et al., 2003; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). However, cross-sectional research comparing adults with adolescents suggests that adults have more impairments in social interaction and have fewer peer relationships than adolescents (Orsmond et al., 2004; Seltzer et al., 2003). Social deficit is persistent and social isolation remains in adulthood (e.g. Friedman et al., 2013; Seltzer et al., 2004). Approximately one quarter to one-third of adults with ASD report having at least one friendship (Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004) and the same percentage report spending time with others in consequence of their hobby, or attend a club or church regularly (Eaves & Ho, 2008). Although highfunctioning adults with ASD do have friendships, their relationships are less close, less empathic, less supportive and less important to the individual, compared to people without ASD (Baron-Cohen & Wheelwright, 2003). However, perceived informal social support is related to quality of life (Renty & Roeyers, 2006) as well as marital adaptation (Renty & Roeyers, 2007) in adults with ASD. To our knowledge, a more comprehensive examination of structural (e.g. size and composition, frequency of contact, initiation of contact, length of the relationship) and functional (e.g. perceived emotional and practical support) characteristics of the social network of adults with ASD from their own perspective is lacking.

In the field of ID more research is conducted regarding social networks than in the field of ASD. With respect to the structural characteristics of social networks of people with ID, research mainly focuses on the number of network members. In their systematic review Verdonschot et al. (2009) concluded that the social networks of people with ID are often small, but the size in the research literature varies from a median of six network members (Robertson et al., 2001) to an average of 11.67 (Lippold & Burns 2009), 14.21 (van Asselt-Goverts, Embregts, & Hendriks, 2013) and 22 (Forrester-Jones et al., 2006) for people with ID living in the community. Differences between studies in the size of the social networks of people with ID might be attributable to the use of different measures: the MSNA (Baars, 1994; van Asselt-Goverts et al., 2013), the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994), the Social Network Guide (Forrester-Jones et al., 2006), or the Social Support Self Report (Lippold & Burns, 2009). Moreover, the observed variation in the size of the social networks reported between studies could be contributed by the design of the study with respect to the informants: the people with ID themselves (van Asselt-Goverts et al., 2013; Forrester-Jones et al., 2006; Lippold & Burns, 2009) versus proxy informants, such as support staff (Robertson et al., 2001). With respect to the functional characteristics, research indicates that social support is perceived mainly from professionals (Forrester-Jones et al., 2006) and that professionals are highly appreciated by individuals with mild ID; for affection comparable with family and acquaintances and for practical/informational support, they are valued even higher (van Asselt-Goverts et al., 2013). Moreover, the majority of the participants (73.1%) are satisfied with their social networks and improvement in the area of strengthening existing ties (e.g. more frequent contact, better contact) is desired, as opposed to expansion of the network (van Asselt-Goverts, Embregts, & Hendriks, 2015). However, these data on both structural and functional characteristics are difficult to interpret because normative data are lacking (van Asselt-Goverts et al., 2013). Even though several researchers have used different groups, most of the times the groups consisted only of people with ID (e.g. difference in age, degree of ID or living accommodation). In one study, people with ID were compared to people with physical disability (PD; Lippold & Burns, 2009), finding that people with ID had more restricted social networks than people with PD, despite being involved in more activities. Widmer et al. (2008) compared individuals with ID, individuals with ID and psychiatric disorders and students matched for age and sex, but only with respect to the family network. Compared with the control group, people with ID less often consider themselves or their family members as sources of emotional support (Widmer et al., 2008).

From this we can conclude that data on the social networks of high-functioning adults with ASD are lacking. Moreover, data on the social networks of people with ID are hard to compare because of differences in methods of data collection (i.e. with respect to measures used and choice of participants) and the lack of normative data. We therefore hypothesized that the networks of people with ASD (Friedman et al., 2013; Seltzer et al., 2004) and the networks of people with mild ID (e.g. Lippold & Burns, 2009; Robertson et al., 2001; Verdonschot et al., 2009) are smaller than those of other people living in the community. However, the number of network members is not a decisive factor in well-being (Lippold & Burns, 2009). In consequence, as well as the usual quantitative approach, focussing on the size of the network, we also used a more qualitative approach, including crucial structural and functional network characteristics ranging from the frequency of social contacts to practical and emotional support (Baars, 1994; van Asselt-Goverts et al., 2013). Moreover, how people themselves perceive their networks is essential (van Asselt-Goverts et al., 2015). Because people with ASD and ID experience difficulties in developing and maintaining social contacts, we focus in this study on their description and their opinions of their networks. Therefore the objective of this study was to determine the specific network characteristics of people with ID and ASD and their specific opinions regarding their networks. Specific research questions were:

1. Are there differences between people with ASD, mild ID and a reference group in their description of structural network characteristics (i.e. size, frequency, length and initiation)?
2. Are there differences between these three groups in their description of functional network characteristics (i.e. affection, connection, preference and practical/informational support)?
3. Are there differences in how the three groups perceive their social network (i.e. satisfaction and wishes)?

4.2 Methods

4.2.1 Participants

Participants met the inclusion criteria if they were young adults, living independently in the community for at least 2 years (i.e. lived in the community alone, with a partner, friend or children; persons living in a group home or with their family were thus excluded from the present study). Moreover, included participants were adults with a mild to borderline ID or adults with ASD and without ID or adults with neither of those disabilities/disorders. The persons with ID were recruited via seven care organizations which were located in the southeast of the Netherlands. The persons with ASD were recruited from two MEE support agencies (organizations that provide mobile advice and support to people with disabilities), located in the east and middle of the Netherlands. The reference group subjects (REF group; i.e. people without ID or ASD) were living in the southeast of the Netherlands and were recruited by students of the HAN University of Applied Sciences. The students were asked to recruit two participants, taking account of age and gender, with respect to the REF group. These two participants were each interviewed by another student who had not been involved in the recruitment. The total sample consisted of 105 persons: 33 persons with mild to borderline ID, 30 persons with ASD and 42 persons in the REF group. The age of the participants varied from 19 to 36 years for both ID and REF group and 19–37 years for the ASD group. The mean age of the participants of the distinct groups did not differ significantly, for the ID group 28.9 (*SD* = 5.2), for the ASD group 29.7 (*SD* = 4.7) and for the REF group 28.4 (*SD* = 4.8), *F*(2, 102) = 0.702, *p* = .498. Although the proportion of men in the ASD group seemed higher, this was not a significant difference (see Table 1).

Table 1 *Demographic characteristics (%) of participants in the ID, ASD and REF group compared*

	ID (*n* = 33)	ASD (*n* = 30)	REF (*n* = 42)	χ2	*p*
Gender (% Male)	48.5	66.7	45.2	3.514	.173
Intimate relationship (% Partner)	51.5	53.3	85.7	12.451	.002
Living situation (% Living together)[a]	30.3	46.7	81.0	20.422	.000
Work situation (% Work & outdoor activities)[b]	78.8	60.0	95.2	13.626	.001

[a] With partner and/or children; [b] A job, supported employment, sheltered workshop, day activity program or school.

Although the three groups were thus matched for age and gender, Table 1 shows that for having an intimate relationship, living situation and work situation the groups did differ significantly. Further analyses showed that the participants of the REF group had a partner significantly more often and lived with this partner and/or their children than both other groups. They also more often had work or outdoor activities during the day. The differences between ID and ASD were not significant on these demographic characteristics.

4.2.2 Measures

Maastricht Social Network Analysis

The structural and functional characteristics of the social networks of the participants in this study were mapped in an interview using the Maastricht Social Network Analysis (MSNA; Baars, 1994). With the MSNA important network members were listed on three cards; one for family members (e.g. partner, parents, siblings and other family members), one for acquaintances (e.g. friends, colleagues, neighbours, other acquaintances) and one for professionals (e.g. support staff, therapists, social workers, coaches). Each member of the network of family and acquaintances was then scored on 20 items. For family and acquaintances, items included structural characteristics (e.g. demographic characteristics, frequency of contact, length of the relationship, initiation of contact) and functional characteristics (i.e. the supportiveness of the contact). The functional characteristics were operationalized along four dimensions: affection (e.g. feeling safe and secure with the person, loving the person), connection (e.g. liking the same things), preference (e.g. preference for contact with the person, liking the contact), and practical/informational support (e.g. being helped by the person when you don't know something or aren't able to do something). Each dimension was measured by one question per network member. For professionals only ten characteristics were used in the MSNA (e.g. frequency of contact, length of the relationship, initiation of contact and functional characteristics), because the other items were less relevant with respect to them (e.g. demographic characteristics). In this study we present the characteristics which are relevant for all groups of network members (e.g. size and composition of the network, frequency of contact, initiation of contact, length of the relationship and the functional characteristics).

To ensure a minimum of reliability and validity for the MSNA, the following were taken as starting points: (a) only information on network members with whom there was a direct connection should be provided; (b) the information obtained in such a manner was of a largely objective, factual nature; and (c) only information which was known for certain was provided, with anything that was uncertain therefore omitted (Baars, 1994).

For the present study, the original form of the MSNA was adapted for use with people with mild ID by simplifying questions and using visualization. This variation was used for all participants, including for participants in the ASD and REF groups. First, a genogram (i.e. family tree) was used to map the characteristics of the participant's family relations. Second, an ecogram was created to visualize the remainder of the social network. This technique, using a diagram with concentric circles around the participant, is described by Phillips, Bernard, Phillipson, & Ogg (2000), referring to Kahn and Antonucci (1980) who first used this technique. We made some adaptations (e.g. in the measure we used we did not include family and we did not determine a maximum of names). Thus, three concentric circles were placed around the name of the participant who then mapped his or her relations with friends, neighbours, colleagues, other acquaintances and professionals by pointing within which circle a particular network member should be placed. The more important the network member, the closer the name is written to the name of the participant. The ecogram we used is outlined in the MSNA manual (van Asselt-Goverts et al., 2012). Finally, a five-point "stairway" scale was used to measure the functional characteristics of the participant's social network in terms of four dimensions of supportiveness: the higher the score, the higher the step on the stairway.

Satisfaction and wishes with regard to the social network

To assess the satisfaction and wishes of the study participants with regard to their social networks, a questionnaire was developed based on the so called "scaling questions" that have their roots in Solution Focused interviewing (de Jong & Berg, 2008; Roeden, Bannink, Maaskant, & Curfs, 2009). The questionnaire consisted of four questions on satisfaction: one question about the network in general (*'How satisfied are you with your social network?'*) and one question about satisfaction with respect to each of the three groups in the network in particular *('How satisfied are you with your network of family/ acquaintances/professionals?'*). Responses were provided along a five-point scale, ranging from very dissatisfied (score 1) to very satisfied (score 5). The five response possibilities were visualized as the five steps of a stairway, as also used in the MSNA. Next, we pointed at the stairway and asked the participant *'What would make the satisfaction with your network one step higher?'* The answers of the participants gave us insight into their wishes with regard to their social network.

4.2.3 Procedure

The scientific and ethics committee from *Dichterbij*, one of the organizations participating in this research, approved the present study. All 105 participants agreed to participate and provided written consent. Interviews were conducted by students at the HAN University of Applied Sciences and social workers from MEE support agencies in the Netherlands. Both groups were trained on how to administer the questionnaires. At the start of the interview, the participant was informed about the aims of the study, that all responses would be handled anonymously and that it was possible to stop the interview at any point. To enhance the reliability of data collection, an interview protocol and accompanying instruction manual was used (van Asselt-Goverts et al., 2012). The interviewers were trained in the use of the protocol and how to conduct an interview. The interviews were voice recorded, and the responses of the participants were also noted during the interviews.

4.2.4 Data analysis

The data were processed and analyzed using SPSS (Version 20). To map the social networks of the participants, both the total network and the different groups within the network were analyzed: family (i.e. partner, children, parents, brothers/sisters and other family members); acquaintances (i.e. friends, colleagues, neighbours and other acquaintances) and professionals. Network members were included in the analyses if they were over the age of 12 years. With respect to wishes, the first expressed wish was coded and categorized further. Decisions concerning the coding and categorization of the wishes were discussed among researchers in the research group.

In the analyses several steps were undertaken. First, mean scores were calculated with regard to the structural characteristics (i.e. size of the social network, frequency of contact, initiation of contact and length of the relationships) and the functional characteristics (i.e. affection, connection, preference and practical/informational support). In a previous article these analyses are described in detail (van Asselt-Goverts et al., 2013). Second, the satisfaction of the participants with their current social networks, and their wishes with regard to these current social networks were determined. Percentages were calculated for this purpose. Third, in order to investigate whether the three groups (ID, ASD and REF) had different social networks, one way ANOVA's (GLM) were performed for continuous outcome variables (i.e. for the structural and functional characteristics) and Chi Squared for categorical variables (i.e. for satisfaction and wishes). When applicable, Post hoc comparisons were conducted to determine which groups differed.

4.3 Results

4.3.1 Structural characteristics of the social networks

Size

Table 2 gives information on the size of the social networks (i.e. the number of network members). On analysis of the number of network members shown on the ecogram (i.e. the visualization of the social network excluding family), there were several significant differences between the three groups. Post hoc comparisons showed that participants with ID or ASD had significantly less network members on the ecogram than participants of the REF group (respectively $p < .001$; $p = .012$). Concerning the average number of network members on the MSNA (i.e. people from both genogram and ecogram who were considered important enough to put them on the MSNA according to the participant), Table 2 also shows differences on all variables except for acquaintances. Compared to the REF group, participants with ASD had a smaller number of network members (*p* = .046), informal network members (*p* = .022) and family members (*p* = .013) on the MSNA. Participants with ID had more professionals on their MSNA than participants with ASD (*p* < .001) and the REF group (*p* < .001). In consequence, the proportion of acquaintances in the network of people with ID was lower than in the network of the REF group, *p* = .020, while the proportion of professionals was higher than in the REF group and the ASD group, *p* < .001.

Table 2 *Size of the social network (Mean, SD) of the ID, ASD and REF groups compared*

	ID		ASD		REF		*F*	*p*
	Mean	SD	Mean	SD	Mean	SD		
Ecogram[a]	9.42	6.1	11.27	7.1	17.86	11.7	9.184	.000
All members on MSNA[b]	14.21	6.5	11.27	5.7	15.00	6.6	3.182	.046
Informal network on MSNA[b]	11.21	6.3	10.30	5.2	14.33	6.7	4.340	.016
Family on MSNA[b]	6.00	3.4	5.20	2.5	7.55	3.9	4.574	.013
Acquaintances on MSNA[b]	5.21	4.2	5.10	3.9	6.79	3.8	2.158	.121
Professionals on MSNA[b]	3.00	1.5	0.97	1.3	0.67	1.1	32.750	.000

[a] An ecogram is a visualization of the social network excluding family; [b] Not all network members of the genogram and ecogram are listed in the MSNA, only the people the participant considered to be important enough to list them on the MSNA.

Frequency of contact

Table 3 presents detailed information on face-to-face contact, contact by telephone and contact by internet in times per year. Only face-to-face contact with acquaintances and internet contact with acquaintances and professionals differed significantly for the three groups. Post hoc comparisons showed participants with ID having more face-to-face contact with their acquaintances compared to both participants with ASD (*p* = .042) and to the REF group (*p* = .003). Moreover, participants with ID had less frequent internet contact with their professionals than the REF group (*p* = .025).

Table 3 *Frequency of contact (times per year; mean, SD) of the ID, ASD and REF group compared*

	ID		ASD		REF		F	p
	Mean	SD	Mean	SD	Mean	SD		
Face to Face								
Family	81.61	58.5	90.80	57.2	95.73	52.4	0.588	.557
Acquaintances	116.96	92.4	63.28	70.1	51.06	38.7	8.737	.000
Professionals	65.95	50.1	56.86	83.8	51.17	69.2	0.299	.743
Telephone								
Family	102.48	172.5	93.63	94.7	116.77	139.6	0.253	.777
Acquaintances	97.41	117.7	74.28	172.1	55.46	56.8	0.999	.372
Professionals	13.11	17.8	69.13	138.6	9.27	12.6	3.152	.051
Internet								
Family	23.67	44.6	31.14	39.9	21.82	22.5	0.648	.525
Acquaintances	52.78	67.9	64.13	93.2	26.36	30.5	3.156	.047
Professionals	2.02	4.0	19.04	28.8	17.22	22.0	3.781	.030

Length of relationships

With respect to the length of the relationships with acquaintances, analyses showed differences (F (2, 97) = 8.289, $p < .001$). Participants with ID knew their acquaintances on average 5.71 years ($SD = 4.9$), participants with ASD 8.55 years ($SD = 3.8$) and participants in the REF group 10.04 years ($SD = 4.4$). Post hoc comparisons showed that participants with ID knew their acquaintances for a shorter length of time than participants with ASD ($p = .048$) and participants of the REF group ($p < .001$). No significant differences were found in the length of the relationships with professionals. Participants with ID knew them on average 3.19 years ($SD = 2.3$); participants with ASD 2.22 years ($SD = 2.4$) and participants of the REF group 2.03 years ($SD = 1.6$).

Initiation of contact

The initiation of contact can be considered as reciprocal (i.e. both the participant and the network member initiate the contact), but it is also possible that the participant or the network member is the main initiator or that neither the participant nor the network member explicitly takes the contact initiative, according to the participant. Analyses revealed very clear differences between the ID, ASD and REF groups in their perception of the initiation, for both family and acquaintances. Post hoc analyses revealed that participants with ID or ASD described their initiative less often as reciprocal than the REF group; this holds for the family network and the network of acquaintances (all $p \leq .005$). Participants with ID saw themselves more often as the main initiator, compared to the REF group, for the family network (*p* = .003) and the network of acquaintances (*p* = .019); while participants with ASD saw their network member more often as the main initiator compared to the REF group (for family not significant; for acquaintances *p* = .040). Participants with ID described more often than the REF group that neither they themselves nor the network member explicitly took the initiative; for acquaintances this difference was significant, *p* = .031. No other significant differences were found.

4.3.2 Functional characteristics of the social networks

In this section we analyzed the differences in the functional characteristics of the social network of the three groups. Table 4 displays these functional characteristics, namely affection, connection, preference and practical/informational support. The three groups differed with respect to (a) affection for family and professionals; (b) connection to family; (c) preference for professionals; and (d) practical and informational support from acquaintances. Post hoc comparisons showed the following results. Regarding affection, participants with ID assigned significantly lower scores to their family than the participants in the REF group, *p* = .017, and higher scores to their professionals, *p* = .003; this latter was also true for participants with ASD compared to the REF group, *p* = .005. Next, participants with ID appeared to feel less connected to their network members compared to both participants in the REF group (*p* = .001) and participants with ASD (*p* = .025) and in particular to their family in comparison with participants in the REF group (*p* = .035). Moreover, both participants with ID and ASD had a higher preference for the contact of their professionals, compared to the participants in the REF group, respectively *p* = .009 and *p* = .020. Finally, the participants in the ASD group perceived less practical/informational support from their acquaintances compared to the REF group, *p* = .039; the difference between participants with ID and ASD with regard to this was only marginally significant, *p* = .053.

Table 4 *Functional network characteristics (Mean, SD) of the ID, ASD and REF groups compared*

	ID		ASD		REF		*F*	*p*
	Mean	SD	Mean	SD	Mean	SD		
Affection								
Family	3.93	0.7	4.16	0.7	4.33	0.4	3.827	.025
Acquaintances	3.80	0.6	4.02	0.8	3.90	0.6	0.754	.473
Professionals	4.00	0.8	4.11	0.9	3.08	1.0	7.328	.001
Connection								
Family	2.91	0.8	3.06	0.8	3.35	0.6	3.484	.034
Acquaintances	3.32	0.8	3.55	0.7	3.65	0.6	2.188	.118
Professionals	2.35	1.1	3.00	1.5	2.71	1.0	1.417	.251
Preference								
Family	4.09	0.6	4.04	0.7	4.27	0.5	1.530	.221
Acquaintances	4.00	0.6	3.99	0.7	4.04	0.6	0.070	.932
Professionals	3.90	0.8	3.94	0.7	3.09	1.1	5.672	.005
Practical/Informational								
Family	3.63	0.8	3.73	0.9	3.87	0.7	0.807	.449
Acquaintances	3.75	1.0	3.22	0.9	3.73	0.7	3.960	.022
Professionals	4.30	0.8	4.33	0.8	3.84	0.9	2.074	.134

4.3.3 Satisfaction and wishes with respect to the social networks

Satisfaction

In Table 5, the degrees of satisfaction of the participants with respect to their social networks in general, but also regarding the family, acquaintances and professionals in their social networks in particular, are presented. From the five-point scale, scores of 1 and 2 were summed as indicators of “dissatisfied” and the same was done for scores 4 and 5 as indicators of “satisfied”. As can be seen in Table 5 the satisfaction scores regarding the total network and the network of acquaintances were differently distributed between the three groups. Further analyses showed that for the total network all groups differed from each other: participants of the REF group were significantly more often satisfied; participants with ID or ASD more often neutral and this latter group was also more often dissatisfied. Moreover, with respect to the satisfaction with the network of acquaintances, participants with ASD reported more often to be neutral or dissatisfied and less often to be satisfied compared to participants of the REF group.

Table 5 *Satisfaction with the social network (%) of the ID, ASD and REF groups compared*

	ID	ASD	REF	$\chi2$	*p*
Network total				30.358	.000
Dissatisfied	3.8	30.0	0.0		
Neutral	23.1	26.7	2.4		
Satisfied	73.1	43.3	97.6		
Family				5.457	.222
Dissatisfied	7.1	10.0	2.4		
Neutral	25.0	33.3	16.7		
Satisfied	67.9	56.7	81.0		
Acquaintances				9.456	.043
Dissatisfied	7.4	23.3	2.6		
Neutral	14.8	20.0	10.5		
Satisfied	77.8	56.7	86.8		
Professionals				6.309	.141
Dissatisfied	11.1	8.0	0.0		
Neutral	7.4	24.0	26.9		
Satisfied	81.5	68.0	73.1		

Wishes

Table 6 presents the wishes with respect to the total network and with respect to the networks of family, acquaintances and professionals separately. The wishes were expressed in response to the open-ended question *'What would make your network one step higher?'*, which was asked with regard to the total network, family, acquaintances, and professionals separately. A large number of the participants did not answer this question or reported having no specific wishes and were excluded from these analyses; for the ID group *n* = 17; for the ASD group *n* = 7 and for the REF group *n* = 9. The reasons for not replying were stated as they were already satisfied, could not come up with something during the interview or found the question too difficult to answer. As Peter[2], a 33 years old man with ASD said:

> *Look, that's just how it is. I don't need that many friends … I don't need to know everybody.*

As can be seen in Table 6, the wishes with respect to family and acquaintances differed between the three groups. First, regarding the family, people with ID wished more frequent contact, while people with ASD desired

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[2] For the sake of anonymity, pseudonyms are used.

better contact with them (e.g. better contact with brother, sister, or family in general, patch up quarrels in the family, more depth in relationships) instead of more frequent contact with them. In the words of Miriam, diagnosed with ASD, mother of three children, two also diagnosed with ASD:

> *More understanding and respect from my parents … I usually have a bad connection with my family. They do not understand me at all, but neither do they understand my children. They have too little knowledge of autism.*

Table 6 *Wishes with respect to the social network (%) of the ID, ASD and REF groups compared*

	ID	ASD	REF	$\chi 2$	*p*
Wishes total network	(*n* = 16)	(*n* = 23)	(*n* = 33)	10.878	.197
More frequent contact	18.8	8.7	33.3		
Better contact	37.5	21.7	21.2		
Expanded network	6.2	21.7	12.1		
Improved social skills	25.0	30.4	9.1		
Other wishes	12.5	17.4	24.2		
Wishes Family	(*n* = 20)	(*n* = 20)	(*n* = 29)	15.550	.027
More frequent contact	50.0	15.0	37.9		
Better contact	15.0	60.0	17.2		
Expanded network	5.0	0.0	3.4		
Improved social skills	10.0	15.0	10.3		
Other wishes	20.0	10.0	31.0		
Wishes Acquaintances	(*n* = 18)	(*n* = 20)	(*n* = 22)	15.687	.034
More frequent contact	22.2	10.0	36.4		
Better contact	44.4	15.0	13.6		
Expanded network	0.0	20.0	9.1		
Improved social skills	27.8	20.0	13.6		
Other wishes	5.6	35.0	27.3		
Wishes Professionals	(*n* = 15)	(*n* = 18)	(*n* = 5)	8.624	.140
More frequent contact	26.7	0.0	20.0		
Better contact	40.0	44.4	40.0		
Expanded network	6.7	0.0	0.0		
Improved social skills	0.0	0.0	0.0		
Other wishes	26.7	55.6	40.0		

Second, also regarding their acquaintances, participants with ID had other wishes than participants with ASD or the REF group; they wished better contact (e.g. having similar interests, wanting more pleasant contact and/or being taken more seriously) with their acquaintances instead of other wishes (e.g. acquaintances dwelling more in the neighbourhood, feeling good, having more elbow-room for personal things). Jessica, a 23 years old woman with ID said, concerning better contact with friends:

> *More real life contact would be nice. I do have contact via MSN, but I would like more normal [face-to-face] contact.*

Regarding their network of acquaintances, people with ASD, more often than people with ID, said they wished to expand their network, for instance with a partner. Elizabeth, a 35 year old woman with ASD told us how difficult it is to get to know more people:

> *I long for many more contacts, but there is so much fear if someone actually comes closer that you clam up and it usually goes wrong again … To say things wrong. Not to respond in time. Not to have an answer when it is expected from you.*

4.4 Discussion

This study provides a comprehensive comparison of the perceptions of people with mild ID, people with ASD and a reference group towards their social networks. We first discuss the hypothesis that the social networks of people with ASD or ID are smaller, and then describe both the similarities and the specific characteristics of the networks of both groups. We finish with a discussion of the implications and limitations of our findings.

4.4.1 The networks of people with ASD and mild ID: size, similarities, specific characteristics

Size was investigated using an ecogram (i.e. outline of all acquaintances and professional network members) and the MSNA. People with ID and people with ASD had less network members on their ecograms compared to the REFgroup, showing that their networks are more restricted. This is in line with previous research showing that the networks of people with ID are generally small (e.g. Lippold & Burns, 2009; Robertson et al., 2001; Verdonschot et al., 2009) and that adults with ASD have fewer friendships (e.g. Howlin et al., 2004; Orsmond et al., 2004). Looking at the MSNA, in which important network members, according to the person, are listed and scored on a number of characteristics, a more detailed picture emerges. People with ASD have fewer informal network members listed on their MSNA compared to the REF group, especially fewer family members. On the other hand, people with ID have more professionals listed on their MSNA compared to both the ASD as the REF group. Remarkably, the people with ID did not have significantly fewer informal network members on their MSNA, although they did have fewer members on their ecogram. This can be explained by the fact that the people with ID put almost all network members from the ecogram on their MSNA, whereas people with ASD, and especially people from the REF group, were more selective. This emphasizes the statement in the introduction section that the measures used are of importance in calculating the size of a social network. Due to its comprehensiveness, the MSNA seems to measure the quality of the most important relationships more than the actual size of the network. In future research we recommend using both the MSNA and the ecogram. In this study the family was mapped in a genogram and not included in the ecogram. In future research it is also recommended to add important family members to the ecogram, in order to get a complete and accurate picture of the social network size.

In addition, other network characteristics, satisfaction and wishes with respect to the network were compared, showing both similarities and differences. Both people with ID as people with ASD felt greater affection and preference for their professional network members compared to the REF group. This can be explained by differences in the nature of this professional support. For people with ID and ASD this support is necessary for daily life, while the REF group often meant the manager or supervisor at work. In actual practice it is important that staff members are aware of their importance in the lives of people with ID or ASD. People with ID or ASD were less often satisfied with their network and more often neutral than the REF group.

Although people with ASD varied widely in their perceptions of the quantity and meaning of their social connections, there were some common factors. People with ASD were more often dissatisfied, especially with their network of acquaintances. People with ASD experienced less practical and informational support from their acquaintances. They wished to expand their network of acquaintances and to improve the quality of their contact with family, instead of having more frequent contact with them. People with ASD saw their acquaintances as main initiators of the contact. A possible explanation is that for many of them, the inability to initiate contact is at the heart of their autistic disorder (American Psychiatric Association, 2013). Indeed, they often wished they had better social skills.

In contrast, people with ID knew their acquaintances for a shorter duration, but saw them more often, compared to both the ASD and the REF group and they wished to improve these contacts. They felt less affection from and connection with family members and wished to have more frequent contact with them. Moreover, people with ID had the feeling that they were the main initiators of their contacts with their network members. The combination of their wish to have more frequent contact and a small network with which they already had high frequency contact might be an explanation of their perception that these network members less often took initiative.

4.4.2 Limitations of the study

Some limitations restrict the interpretation of our findings. First, the inclusion criteria (e.g. young adults, living independently in the community) may limit generalization of the findings to younger or older people or people with more severe ID or ASD symptoms or to people living in group homes or with their parents. For instance, research shows that high-functioning adults with ASD are living with their parents in more than 50% of cases (Renty & Roeyers, 2006), so it is possible that the participants in our sample had better social skills than other high-functioning adults with ASD. The variation of the sample sources between the groups in this study was another potential limitation. The finding that the ID group has more professionals in their networks is possibly due to the fact that the ID participants were recruited via care organizations, from which they still received mobile support, while the ASD participants were recruited from a support agency giving support or advice.

Next, data were collected using self-report measures. Although it is possible that people with ID or ASD see themselves as more or less socially involved than others would report (Kasari et al., 2011), the use of proxies also has disadvantages. According to Verdugo et al. (2005), proxies should only be used when absolutely necessary, due to significant communication limitations which was not the case in this study. We tried to increase the reliability of self-reports of people with ID or ASD by adapting the measures, by simplifying the questions and by using visualization. Although we tried to ensure that the questions were not too difficult, in the section on wishes several participants couldn't give an answer or specific wishes. Although it is possible that they indeed did not have any wishes, we have to consider the possibility that for some participants these questions were too complicated or too abstract. Overall, future research with other groups of participants is recommended. Gathering additional data from proxies is also recommended, when future results involves people with more severe ID or ASD.

Moreover, we did not focus on stressful characteristics of the network members, such as conflicts or the presence of ID, ASD or behavioural problems in network members. As such, network members can have a harmful rather than a beneficial influence (Lunsky & Havercamp, 1999). It is important to focus more on these issues, because it provides insight into the vulnerability of the network.

In this type of research it is always a challenge to obtain data from a sample size large enough to have sufficient power. Our sample size of 105 spread over three groups (ID, ASD and the reference group) gave a power of .80 and an effect-size of .30. This is slightly higher than .25, which is classified as a medium effect by Cohen (1992). Because differences with a small effect will not have been picked up in this study, we recommend repeating the study with a larger sample size.

Finally, this study does not indicate whether social inclusion for people with ID or ASD living in the community is a realistic possibility. Can network interventions alter social networks? In what way does training about networks affect the lives and social networks of people with disabilities? Relevant questions, requiring future research, because there is a critical need for evidence-based interventions to address social inclusion (Friedman et al., 2013).

4.4.3 Practical implications of the study

It has been shown that social support benefits both physical and mental health and is related to lower rates of morbidity and mortality in the general population (e.g. Cohen & Wills, 1985; Holt-Lunstad, Smith, & Layton, 2010; Umberson & Montez, 2010). Although there is no evidence yet for this benefit in people with ID (Emerson & Hatton, 2008; Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011), associations between social support and quality of life for adults with ASD (Khanna, Jariwala-Parikh, West-Strum, & Mahabaleshwarkar, 2014; Renty

& Roeyers, 2006), for parents of people with ASD (Benson, 2012; Pozo, Sarriá, & Brioso, 2013) and for adults with ID (van Asselt-Goverts et al., 2015; Bramston, Chipuer, & Pretty, 2005; Lunsky & Benson, 2001; Miller & Chan, 2008) have been shown. For people with ASD, comorbidity with psychiatric disorders, such as mood and anxiety disorders, is very common (Hofvander et al., 2009; Mazzone, Ruta, & Reale, 2012; Seltzer et al., 2004). Moreover, people with ASD report lower health related quality of life than the general population (Khanna et al., 2014) and people with ID experience health inequalities (Emerson & Hatton, 2008). In the onset, expression and severity of these mental health problems, the environmental context may play an important role and social support might contribute to a decrease of these problems (Mazzone et al., 2012). Increasing health through social network enhancement might save health care expenses. This underlines the importance of social network interventions for people with ASD and ID.

Although both people with ID and people with ASD experience difficulties in developing and maintaining social contacts, the present research shows that each group has its own issues with regard to social network characteristics, satisfaction and wishes. Support staff should adapt to these network characteristics and to the needs and wishes with respect to the social networks to facilitate their social inclusion and as a consequence enhance their quality of life. For instance, in actual practice it can be useful to explore the reasons for a client perceiving him/herself or the network member as the main initiator of contact and support him/her to a more reciprocal initiation of these contacts. To adapt to network characteristics it is also recommended to use, in day-to-day practice, both the MSNA and the ecogram, because both measures have merits and limitations. In addition, the measure of satisfaction and wishes used in this research would also be useful for support staff. To facilitate social inclusion, the training of professionals may be necessary, for instance along the lines of Person Centered Planning (PCP; O'Brien, Pearpoint, & Kahn, 2010). Because research shows that people with ASD are less likely to have a PCP plan (Claes, van Hove, Vandevelde, van Loon, & Schalock, 2010; Robertson et al., 2007), future research on PCP with people with ASD is recommended. In the Netherlands an equivalent of PCP is available for people with mild ID; in this training offered by a self-advocacy group, they learn to map their network, their dreams and goals, their gifts, strengths and talents and to plan a meeting with network members (Blommendaal & van de Lustgraaf, 2006). Because, in actual practice, it is a challenge to strengthen and expand the social networks, such training for professionals or clients should be followed by coaching (van Asselt-Goverts et al., 2014). Moreover, these social network interventions should be examined for effectiveness, which is still an almost unexplored area in the care for people with ID and ASD.

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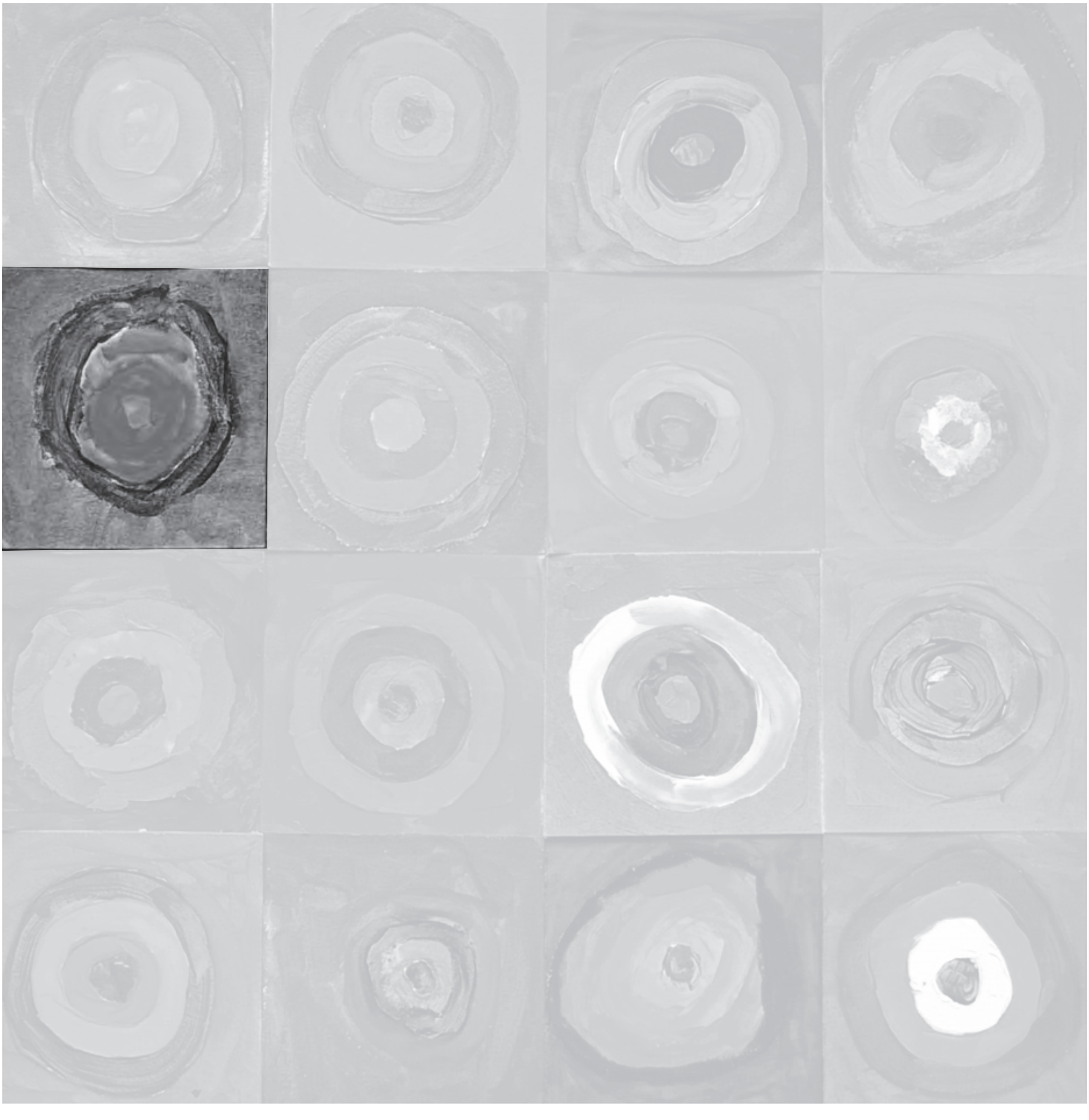

Chapter 5

Experiences of support staff with expanding and strengthening social networks of people with mild intellectual disabilities

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Abstract

A supportive social network is crucial for facilitating social inclusion. The social networks of people with intellectual disabilities (ID) are often small and typically include very little contact with friends and acquaintances who do not have ID. Professionals can play an important role in strengthening and expanding the social networks of clients. In this study, experiences with interventions aimed at doing this were examined. Six group interviews were held with a total of 27 professionals. The results showed interventions to strengthen social networks (e.g. attention to the maintenance of contact with network members) and interventions to expand social networks (e.g. participation in leisure time activities and working with volunteers). However, a large number of impeding factors was mentioned, such as the limited size of the social networks, characteristics of the client, different perceptions and clients falling between the cracks when it comes to leisure time. The large number of impeding factors shows the strengthening and expansion of social networks to be complicated in actual practice. Recommendations are thus made to strengthen and expand the social networks of clients in an innovative manner which also takes these impeding factors into account.

5.1 Introduction

Support for people with intellectual disabilities (ID) has greatly changed over the past few decades. First, the focus has shifted from limitations on intelligence and skills to the person functioning as a whole. Second, the concept of 'quality of life' has been introduced into the care for people with ID and used to evaluate their general well-being, which includes their rights, participation in society, autonomy, independence, choices, emotional well-being, personal development and social inclusion (Buntinx & Schalock, 2010). With respect to social inclusion, two main aspects have gained importance: interaction with others — including friends, family and people in the community — and participation in community activities (Abbott & McConkey, 2006; McConkey & Collins, 2010a). Finally, individualized support is increasingly being provided to enhance the quality of life for people with ID (Buntinx & Schalock, 2010).

Worldwide, these developments have been translated into policy resulting in more and more people with ID living and working in the community. Research shows advantages of such social inclusion, moreover. For example, people living in supported living accommodation (i.e. dwelling in an ordinary house or apartment in the community with visiting support from professionals) tend to have more social contact than those living in a group or residential care (McConkey, 2007; Robertson et al., 2001). Physical presence in the community, however, does not guarantee greater social inclusion just as taking part in an activity does not guarantee meaningful social contact, particularly with people without ID (Ager, Myers, Kerr, Myles, & Green, 2001). When people with ID live and work in society, they can — in fact — easily fall into isolation (Chenoweth & Stehlik, 2004). Their social networks are generally small (e.g. Lippold & Burns, 2009; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009), and they typically include very little contact with people who do not have ID (i.e. only families and caregivers in this regard) (e.g. Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011; Lippold & Burns, 2009; Verdonschot et al., 2009).

Research shows people with ID to perceive several barriers to social inclusion. The barriers include a lack of the necessary knowledge and skills; the location of their homes; various community factors; and the roles played by support staff (Abbott & McConkey, 2006). With respect to the roles of support staff, research shows staff members to pay greater attention to care tasks than to social inclusion tasks (McConkey & Collins, 2010a). The well-intended efforts of support organizations and support staff may even limit social inclusion at times. Research on the neighbouring of people with ID (van Alphen, Dijker, van den Borne, & Curfs, 2009), for example, shows that the location of the homes of people with ID to sometimes act as a physical barrier to neighbourly interactions when there is no shared space to meet or see other people (e.g. bordering gardens, a shared driveway). Organizing social activities and even doing favours within the support organization may also limit neighbouring (van Alphen et al., 2009). People with ID report insufficient availability of staff members (i.e. not enough one-on-one staff time) to help promote community participation (Abbott & McConkey, 2006). Not only the organization but also support staff themselves can limit inclusion by imposing rules such as not allowing people to go out alone or to talk to strangers (Abbott & McConkey, 2006; van Alphen et al., 2009).

These findings are important because we know that support staff can play an important role in the facilitation of social inclusion (Abbott & McConkey, 2006; Todd, 2000; van Alphen et al., 2009). If social networks are small and social support is perceived as insufficient, support staff can undertake network interventions to expand and strengthen social networks. Various network interventions are described in the literature on social networks in general (Heaney & Israel, 2008) and more specifically in the field of mental health care (Biegel, Tracy, & Corvo, 1994; Pinto, 2006). In all cases, a distinction between expanding the social network with new contacts and strengthening existing ties, such as family ties, is made (Biegel et al., 1994; Pinto, 2006). Group interventions involving self-help groups can also be used to expand social networks, increase friendships and decrease loneliness (Perese & Wolf, 2005). In their comprehensive review of 100 studies on the effectiveness of social network interventions, Hogan, Linden and Najarian (2002) distinguished group versus individual interventions, professional- versus peer-guided interventions and interventions with a focus on social skills versus expansion of the social network and increasing perceived support. Noteworthy was that none of the 100 studies concerned people with ID. Research on social network interventions and their effects in the field of ID is thus rare.

One of the few studies of social network interventions for people with ID reviewed the effectiveness of interventions aimed at increasing the social interactions of adolescents with ID and their general education peers (Carter & Hughes, 2005). In this research a distinction was made between skill-based interventions and support-based interventions. Both interventions appeared to be effective and a combination of interventions is recommended (Carter & Hughes, 2005). A second study involved a 'social participation project' in which people with ID or a psychiatric disorder participated. A total of 10 specific interventions or improvements were reported and varied from mapping client needs/wishes to deploying volunteers (Broer, Nieboer, Strating, Michon, & Bal, 2011). Many of the teams reported using the interventions before the project was initiated but nevertheless using them in a better way following intervention; only a few new interventions concerning the neighbourhood and the community had to be introduced (Broer et al., 2011). In the end, clients' social networks did not expand as a result of the project, but they did experience less loneliness. A distinction was made between an individualizing approach with a focus on individual clients and their wishes versus a normalization approach with a focus on increased participation in the 'normal' community (Broer et al., 2011).

In sum, we know that the social networks of people with ID are important and which types of social network interventions exist, but we do not know the extent to which and how support staff for young adults with mild ID use available network interventions. Before undertaking an intervention, thus, it is important that the workability of the intervention be examined. And the objective of the present research was therefore to explore the experiences of professionals with regard to strengthening and expanding the social networks of clients with mild ID.

5.2 Method

5.2.1 Participants and setting

A total of 27 professionals, employed by six support organizations located in the southeast of the Netherlands were interviewed. The professionals all worked with young adults with mild ID. At each of the organizations, a single group interview was organized with psychologists, support staff and — at one organization — a social worker. A total of six group interviews was thus held with 15 support staff, 11 psychologists and one social worker.

5.2.2 Instruments

Semi-structured interviews were conducted by two interviewers with the aid of an interview protocol. The participants were asked about what they did to strengthen and expand the social networks of their clients during their current work.

5.2.3 Procedure

Standard content analyses based on a general inductive approach (Thomas, 2006) were conducted as our aim was to discover the experiences and opinions of professionals without prior assumptions, theories or hypotheses guiding our exploration. Several procedures were included in the approach (Thomas, 2006).

1. Preparation of the raw data files. The interviews were voice recorded and transcribed. Transcription guidelines were formulated for how to handle silences, intonation and difficult or unintelligible speech such that the transcription was done in a consistent and unambiguous manner.
2. Close reading of the text. The transcripts were read in detail until the researcher was familiar with the content.
3. Creation of categories. The transcripts were coded and analyzed with the help of the ATLAS.ti, version 6.6.1 (Muhr, 1993). The data were divided into manageable units for purposes of data reduction: quotations. Codes were not created a priori but, rather, developed during the coding of the quotations and thus on the basis of the content of the interview responses.
4. Overlapping coding. Quotations could be assigned more than one code. The transcription of the present research was divided into 381 quotations, and 392 codes were assigned to the quotations.

5. Continuing revision and refinement of the categorization system. The coding was discussed in four rounds with the co-authors of the manuscript who are jointly experts on interventions with people with mild ID and qualitative data analysis. Guidelines were established for determining the length of the quotations to be coded and the assignment of the codes. Codes were adjusted as needed: some codes were collapsed; some codes were divided into more codes; and some new codes were created. The outcome was a list of 62 codes. Next, those codes which related to the same content were gathered together in a single category. As a result, the 62 codes were reduced to four categories of codes.

5.2.4 Reliability

To ensure sufficient reliability (i.e. precision and unambiguity of the coding process), we followed the aforementioned steps. Summarize briefly: (a) establishment of an interview protocol and list of topics; (b) conduct of the interviews by two interviewers; (c) voice recording and transcription of the interviews; (d) establishment of a list of codes with clear definitions following four rounds of discussion with experts; and (e) formulation of guidelines.

In addition, coding consistency checks were conducted: (a) independent parallel coding; (b) a stakeholder check, to which a member of each of the six organizations was invited; and (c) a check on the clarity of categories (Thomas, 2006). With respect to the last check, a second researcher coded two of the six interviews using the list of codes after all of the interviews were coded. The interrater agreement was 83.33%. Finally, the quotations used to illustrate the findings were translated and checked by a native speaker of English.

5.3 Results

5.3.1 Number of quotations, codes and coding categories

The transcripts of the group interviews were divided into 381 quotations concerning the experiences of the professionals with strengthening and expanding the social networks of their clients. As already mentioned, a total of 62 different codes were developed and applied to the interview quotations. The codes could be clustered into four general categories: *interventions to* *strengthen social networks, interventions to expand social networks, impeding factors* and *facilitating factors*. Some of the quotations were assigned more than one code, which meant that a total of 392 codes were assigned in the end. In Table 1, the number of codes and frequencies for the four general coding categories are presented.

Table 1 *Number of codes and frequencies for four general coding categories*

Category	Number of codes	Number of quotations
1. Interventions to strengthen social networks	14	61
2. Interventions to expand social networks	13	86
How to expand?	9	47
Expand with whom?	4	39
3. Impeding factors	24	180
4. Facilitating factors	11	65
Total	62	392

5.3.2 Strengthening the social network

The category ‘interventions to strengthen social networks’ included interventions aimed at strengthening already existing relations with members of the social network. A total of 14 interventions to strengthen the social network stood out in the interviews. As can be seen from Table 2, many quotations (nine) concerned attention to the maintenance of the existing social network by, for example, stimulating the client to give someone a call. According to one participant:

> *You maintain it [the network] by sending that little card or something like that, but that is where they really need help. ‘Cause if that doesn’t happen, then it [the network] disintegrates.*

In eight of the quotations, it was mentioned that the client was encouraged to more frequently call upon members of his or her network for help. For example, when the client asks for support, the professional can ask the client which member of his or her network might be able to provide him or her with this support. Such an approach is also effective during a crisis, as witnessed by the following example from a staff member supporting parents with ID and their child:

> *The situation which we had last when a child had to be removed from the home was really intense. … What I decided to do, at the advice of my colleagues, was to call — together with the clients — their parents and inform them. …. Ninety minutes later, after a really intense period, I was able to leave the house because it was full of family. … Those families really put their powers together while the contact before that was not really strong. The one family arranged for a lawyer; the other inquired as to rights.*

Remarkably, such an intervention was only mentioned in two of the six interviews. In almost all of the group interviews (i.e. five out of the six), it stood out that the social network could be strengthened by discussing disturbances such as misunderstandings, problems, bottlenecks (seven quotations).

5.3.3 Expansion of the social network

The category 'interventions to expand social networks' included interventions aimed at enlarging the social network. The group interviews revealed 13 different interventions which could be clustered into two subcategories: 'how to expand?' (nine codes) and 'expand with whom?' (four codes). As can be seen from Table 2, expansion of the social network was most often stimulated by encouraging clients to attend an organized leisure time activity (19 quotations and in all six interviews). According to one participant:

> *We thus discuss things, 'What are your interests? Do you want to join a sports club? ... Where can you find information on a club? ... How are you going to get there? … Who is going to go with you to a trial session?' … That's how we prepare things in little tiny steps.*

Table 2 *Social network interventions*

Type intervention	Number of interviews	Number of quotations*
Strengthening social networks	6	61
Attend to maintenance of network	4	9
Encourage to call upon network more often	2	8
Discuss disturbances	5	7
Teach social skills	3	6
Share and exchange information	4	5
Psycho-education	4	5
Restore contact	2	5
Inform network members of their importance	3	4
Support network members	2	3
Mention positive things	2	2
Map social networks	2	2
Show interest	2	2
Discuss differences in opinion	1	2
Contact professionals of network members	1	1
Expanding social networks	6	86
How to expand?		
Get client involved in leisure time activities	6	19
Joint activities	4	9
Internet use	4	7
Education/work	2	4
Get client involved in volunteer work	2	4
Be of service to others	1	1
No internal specialized care	1	1
Teach social skills	1	1
Create 'spontaneous' meetings	1	1
Expand with whom?		
Look for a volunteer	5	12
Look for a partner	6	10
Neighbourhood	3	9
Other clients in the organization	4	8

*Out of a total of 392 quotations.

Respondents also frequently mentioned participation in unorganized activities: having a cup of tea, watching a DVD together, cooking or playing a game with a network member (nine times). Searching for contacts via internet was brought forth seven times. Stimulating clients to be of service, themselves, to others (e.g. get involved in neighbourhood help, volunteer work) occurred in only five quotations and in only two of the interviews. An example of the latter strategy was:

> *An older woman who doesn't want to walk the dog in this weather and a client who loves to walk a dog, you get some reciprocity.*

Looking for a volunteer within the subcategory 'expand with whom?' was also often mentioned (12 quotations). In 10 quotations, it was indicated that clients have a desire for a relationship and thus need to search for this. In addition, making contacts in the neighbourhood in order to expand their social network to include neighbours without ID was frequently mentioned (nine times). An example is:

> *We also have rabbits outside and the neighbours come over with their children to watch the rabbits.*

Stimulating contact with other clients receiving support from the same organization was mentioned eight times.

5.3.4 Impeding factors

During the interviews, the professionals mentioned 24 factors which complicated the process of strengthening and expanding the social networks of clients. These factors have been clustered into the category 'impeding factors.' Those codes assigned more than five times are listed in Table 3.

Many (24) quotations concerned the fact that the social networks for this group of clients are often small and that clients have no intimate or close social contacts. Another impeding factor consisted of characteristics of the client: not feeling accepted, lack of social skills and difficulties with acceptance of the disability, adaptation or taking the initiative. In the words of one professional:

> *They [the people with ID] often cannot sense very well if people have good intentions or just the opposite.*

A total of seven quotations concerned multiple problems, including behaviour and addiction problems. The professionals further indicated in 17 quotations that the clients viewed their social networks differently than the support staff. As one professional said:

> *The client often does not see what a network can do for him or her.*

When it comes to leisure time, the professionals indicated in 12 quotations that people with mild ID are not involved enough in regular leisure time activities but also do not feel at home in leisure time activities organized for people with ID. In other words, clients frequently fall between the cracks. As one professional worded it:

> *This target group [people with mild ID] often fall by the wayside. And they are really running into this right now. They don't feel disabled. They feel too good for people with an intellectual disability but can't quite make it at clubs for people with average intelligence.*

It was also pointed out in 12 quotations that there is too little time and money to strengthen or expand the social networks of clients. As one of the staff members put it:

> *If a client has many needs and you have only two hours a week to provide support, careful consideration of which support need you are going to invest your time in is needed. ... I think mapping, strengthening and expanding the social network of the client is important, but I sometimes wonder: "When?"*

5.3.5 Facilitating factors

During all of the interviews, 11 factors were mentioned as clearly facilitative for strengthening and expanding the social networks of clients. As can be seen from Table 3, it was mentioned on 12 occasions that working with social networks is shaped by the client's support plan. The client's social network can be mapped as part of the development of the support plan, and a detected need to strengthen or expand the network translated into a support need. The support plan can be used to specify which social network member does what and which member of the social network can help realize the support plan. The importance of matching interests was mentioned on 11 occasions. The interests of clients must be inventoried in order to identify a suitable leisure activity and/or social network member with similar interests. As one staff member said:

> *I have done that [looked at the desires and interests of a client] ... and he said … "I used to go fishing with my father all the time and I really, really liked that and I actually don't do that anymore." ... Given this, I took a look at the possibilities in the neighbourhood. And then someone moved into the flat and he sometimes went fishing in the summer. ... So we approached him: "What would you think of taking him along once in a while?" And he said: "Sure, I'd like to do that sometime."*

Table 3 *Impeding and facilitating factors*

Type factor	Number of interviews	Number of quotations*
Impeding factors	6	180
Limited size social network	5	24
Characteristics of client	6	23
Different perceptions	6	17
Falling between cracks	5	12
Too little time/money	4	12
Staff members in social network too close to client	4	10
Cutbacks/government regulation	4	9
Multiple problems	4	7
Characteristics of the social network	1	7
Risks of internet use	4	6
Lack of volunteers	3	6
Complex social network	3	6
Loneliness	3	6
Other codes (11)		35
Facilitating factors	6	65
Social network in support plan	5	12
Matching of interests	4	11
Awareness	4	9
Continuing education courses and programmes	4	8
Methods and theory	3	7
Customization/individualized approach	3	6
Other codes (5)		12

*Out of a total of 392 quotations.

Another nine quotations indicated that support staff should work to raise awareness among clients of the importance of having a social network and help provide insight into their functioning with respect to such. It was mentioned in only two interviews that cutbacks and regulations could also be viewed positively, namely as encouraging support staff and clients to involve network members. It was mentioned in only one interview that working with social networks could be stimulated by collaborating with other organizations at the level of management.

5.4 Discussion

5.4.1 Main results related to literature

In this research, we examined the manner in which providers of support services help strengthen and expand the social networks of clients with mild ID. The results showed the professionals to report a total of 14 interventions undertaken to strengthen social networks and 13 interventions undertaken to expand them. Strengthening and enhancing existing social links appear to be called for when existing network ties offer as yet untapped potential. Expanding and developing new social links appear to be useful when the existing network is small, overburdened or unable to provide effective support (Heaney & Israel, 2008).

Working with social networks is nevertheless reported to be difficult: 24 impeding factors were mentioned in 180 quotations in our research. Research on inclusive practices has shown value orientation, seeing the advantages of inclusion, having the necessary methods and knowing how to deal with bureaucracy as important factors for promoting inclusion (Kröber & Verdonschot, 2012). The impeding factors mentioned in the present research might reflect the negative experiences of the professionals with working with social networks. And these negative experiences might influence the value orientations of professionals towards social inclusion and negatively influence their work to facilitate inclusion.

Impeding factors include too little time and money and having to deal with cutbacks and regulations. Increased bureaucracy, together with little time and money, presumably affects the ability of professionals to meet the needs of clients (Hermsen, Embregts, Hendriks, & Frielink, 2014). Though these factors were indeed mostly mentioned as impeding in our interviews, some participants nevertheless emphasized that they could also function as facilitating factors as they underline the need for a social network. Inventiveness, creativity and acting proactively are necessary characteristics among support staff to deal with cutbacks and regulations (Hermsen et al., 2014; Kröber & Verdonschot, 2012). Another complicating factor is the difference in the perceptions of professionals versus clients. On the one hand, according to professionals, clients perceive the importance and significance of their social networks differently than professionals do. In other research, the case managers for clients with psychiatric disorders also reported clients not having an interest in social networks or a desire to call upon network members for support (Biegel, Tracy, & Song, 1995). On the other hand people with ID also perceive service policies and the way in which they are treated by support staff as inhibiting community participation, e.g. not treated like an adult or not allowed to go out alone (Abbott & McConkey, 2006). Raising awareness of the importance of social networks and community involvement is thus necessary. Moreover, the presence of people with ID in community-based organizations is necessary to create a context of inclusion (O'Brien, 1989); only then can people with ID participate in activities with other citizens, neighbours and colleagues (O'Brien, Pearpoint, & Kahn, 2010).

In addition, support staff must also be made aware of the need to take the personal traits of clients and specific characteristics of their social networks into account when planning network interventions (Pinto, 2006). One possibility for the realization of more customized support is to examine the interests of the client more carefully and strive to bring people with similar interests together (Lunsky, 2006). Another possibility is to literally translate the social network needs and desires of the client into well-defined support needs and goals within the individual support plan. Goal setting appears to be a suitable means to promote social inclusion and can clearly be tailored to individual needs and aspirations (McConkey & Collins, 2010b). Participatory assessment processes which require individuals to identify the strengths and weaknesses of their own social networks can thus help tailor interventions to the needs of clients and thereby make the interventions effective (Heaney & Israel, 2008).

5.4.2 Implications for practice

Strengthening and expanding the social networks of people with ID also call for the conduct of both individual and community level interventions (Lunsky, 2006). In order to do this, it is critical that staff members identify — in cooperation with the client — which member(s) of the social network can help meet a specific need of the client. This strategy was highlighted in two of the interviews in the present research and should be given greater attention in the future. When the size of the client's social network is limited, for example, registration with a volunteer organization is worth considering, but also searching for one of the neighbours to provide support. Research on neighbouring with respect to people with ID shows that interpersonal relationships between neighbours with and without ID should not be simplified in terms of attitudes which are primarily prejudiced/stigmatizing versus entirely accepting. Instead, it shows a more complex picture of sometimes ambivalent thoughts, feelings and interaction needs (Dijker, van Alphen, Bos, van den Borne, & Curfs, 2011). Taking all of this into account, support staff must thus help clients and neighbours identify mutually acceptable forms of neighbouring and when additional support should be called upon to improve interactions or handle conflicts, for example (van Alphen, Dijker, van den Borne, & Curfs, 2010).

The support worker is a bridge to the wider community and should provide opportunities for participation in social, school, work and religious settings (Abbott & McConkey, 2006), but also in leisure time organizations. Support staff should have up-to-date information on community facilities and activities; they can also be the ones to teach community members within such settings to be more sensitive to the needs of individuals with ID and thereby contribute to the change of attitudes and motivation of the community to provide a positive welcome for people with ID in the community (Abbott & McConkey, 2006; Lunsky, 2006). Facilitating organizations are organizations that are willing to collaborate with other organizations and think beyond the level of the single individual or single organization (Schalock, Verdugo, Bonham, Fantova, & van Loon, 2008; van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2011). As this was mentioned in only one interview, however, more attention should be paid to interventions at the level of the organization. Moreover, organizations should facilitate and stimulate professionals in working creatively on social inclusion instead of restricting them with the imposition of rigid regulations (Hermsen et al., 2014).

Working with social networks thus requires support staff to concentrate on client needs but also mediate between client and society (Todd, 2000; van Alphen et al., 2010). In such a manner, opportunities can be created for clients to participate in society. That is, support staff and clients must identify not only what *others* can mean for clients but also what *clients* can mean for others. This strategy was highlighted in two of the interviews in the present research and merits greater attention, particularly in light of the fact that reciprocity is a key factor for the maintenance of supportive relationships over time and involves various forms of exchange (Biegel et al., 1994; Ferlander, 2007; Lunsky, 2006). Support staff can thus stimulate clients to offer neighbourly help, undertake volunteer work or do something for family members, the sport club or the church — provided this fits with the interests of the client. The strengthening and expansion of social networks require that clients realize the importance of the social network, as motivation is one of the variables which should be taken into account when initiating an intervention to improve relationships (Lunsky, 2006).

5.4.3 Limitations of the research

The present research has some possible limitations. The focus was on young adults with mild ID, which means that the results cannot be generalized to other target groups such as clients in a different age category or clients with a different degree of ID. Moreover, the perspectives of the professionals stood central in the present research; clients did not participate in the group interviews. The views of the clients will be particularly useful as the present results shows clients often view their social networks differently than support staff. It is therefore recommended that the following topics be considered in future research: how do people with mild ID view social networks, how satisfied are people with mild ID with their social networks and what wishes do people with mild ID have with respect to their social networks? The wider community can help and hinder the development and maintenance of social networks and relationships via attitudes and the acceptance or rejection of people with ID. In the future, more thorough investigation of interventions at the meso and macro levels including the role of organizations as a bridge to the wider community may thus be worthwhile. Finally, the extent to which support organizations actually conduct network interventions and the effectiveness of the interventions, if any, was not examined in the present research. However, the success stories and impeding factors mentioned in the interviews provided some indication of the workability and effectiveness of various interventions. It is nevertheless recommended that interventions for strengthening and expanding the social networks of people with ID be examined more systematically and evaluated for their effectiveness in the future.

5.4.4 Conclusion

The present study contributes to the inclusion paradigm, especially with respect to the critical role of professionals. Although professionals are aware of the importance of social networks and interventions to expand and strengthen the social networks of people with ID, interventions aimed at doing this have been mostly conducted at the level of the individual and not the community to date. In actual practice, it is hard to strengthen and expand the social networks of individuals with ID as witnessed by the number of impeding factors reported in our study and statements with regard to such. Social inclusion is apparently hard to achieve, despite the influence of the inclusion paradigm, despite physical integration and despite the training of professionals on inclusion over the past few decades. This study adds to the literature on what specific barriers professionals experience in working with the social networks of people with ID.

The present findings are also of importance for actual practice. Support organizations can pay greater attention to possibly impeding factors when working to strengthen and expand the social networks of clients. The previously described recommendations provide a starting point for doing this. During network interventions, the contact must not be rigid or unidirectional, and the creation of a care-related relationship of dependency should be avoided (van Alphen et al., 2009). The members of a client's social network should be recognized as private individuals and not as unpaid professionals who can be expected to tackle things in a methodical manner (van Heijst, 2008). Network members should not be construed as a cheap source of support in times of cutbacks but, rather, as a valuable resource in light of people's need for connection and affection (Baars, 1994).

To *facilitate* social inclusion, the training of professionals may be offered along the lines of Person Centered Planning (O'Brien et al., 2010) or the Tool-Kit on Social Inclusion (Collins & McConkey, 2007). However, consideration of the impeding factors revealed in this study suggests that in-service training may not be enough. Training which aims to change the behaviour of a client and also the behaviour of the broader network or community may call for a training format in which in-service training is combined with on-the-job coaching (van Oorsouw, Embregts, Bosman, & Jahoda, 2009). And in such a training and coaching programme, attention must be paid to potentially impeding factors and how to tackle them as real social inclusion will otherwise remain an ideal and not become a reality for people with ID.

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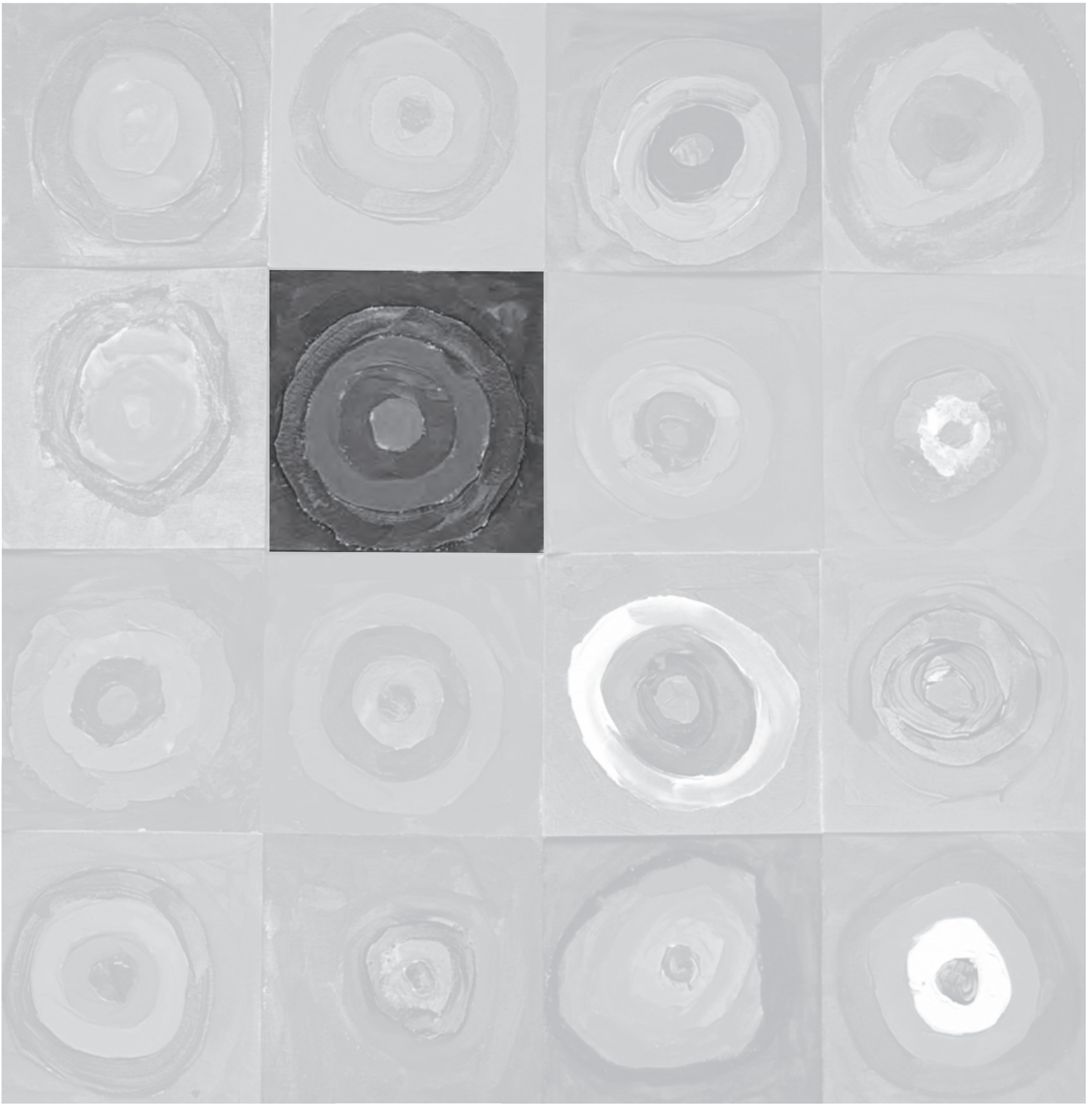

Chapter 6

Evaluation of a social network intervention for people with mild to borderline intellectual disabilities

This chapter is submitted for publication as:

Asselt-Goverts, A. E. van, Embregts, P. J. C. M., & Hendriks, A. H. C. (submitted). Evaluation of a social network intervention for people with mild to borderline intellectual disabilities.

Abstract

Background: Little is known about the effectiveness of interventions aimed at enhancing the social networks of people with intellectual disabilities (ID). This study explores the results of such an intervention. What did participants learn from the intervention? Were there any changes in network characteristics, satisfaction and wishes in relation to networks, participation, loneliness, self-determination or self-esteem?

Method: The results of the intervention in the lives of five participants with mild to borderline ID was explored from several perspectives (i.e. participants with ID, their support workers and trainers), using mixed methods (i.e. interviews and questionnaires).

Results: The analysis revealed the vulnerability of participants and their networks but also the benefits experienced from the intervention, such as decreased loneliness, enhanced social networks, increased awareness, competence, autonomy and increased participation.

Conclusion: The indicative level of evidence for the effectiveness of this intervention, justifies a larger series of case studies or a larger control trial study.

6.1 Introduction

Social inclusion is generally seen as an important factor for the quality of life of people with intellectual disabilities (ID) (Schalock, 2004) and focuses on two domains, social relationships and community participation, that mutually support each other (McConkey & Collins, 2010; Simplican, Leader, Kosciulek, & Leahy, 2015). Social relationships and community participation are influenced by individual, interpersonal, organizational, community and socio-political factors (Simplican et al., 2015). With respect to socio-political factors, the importance of social inclusion, participation and social relationships is acknowledged worldwide, for instance in the United Nations Convention of the Rights of Persons with Disabilities (United Nations, 2006) and in policy in Australia (Commonwealth of Australia, 2011), in the United Kingdom (Department of Health, 2009) and in the Netherlands (Social Support Act, Wet maatschappelijke ondersteuning, 2015). However, the aims of these policies cause major challenges due to several factors. With respect to individual factors research shows that people with ID experience lower self-esteem (Valås, 1999), less autonomy and decreased well-being (Sheppard-Jones, 2003). Moreover, their social networks are restricted in several ways (an interpersonal factor). With respect to the structural characteristics of social networks, their networks are small (e.g. Lippold & Burns, 2009; Robertson et al., 2001; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). In comparison with other members of their community, people with ID have known their acquaintances for a shorter duration, see them more often and have the feeling that they themselves are the main initiators of contacts with their network members (van Asselt-Goverts, Embregts, Hendriks, Wegman, & Teunisse, 2015b). With respect to the functional characteristics (e.g. emotional or practical support), support is perceived as coming mainly from professionals (Forrester-Jones et al., 2006; van Asselt-Goverts, Embregts, & Hendriks, 2013). Moreover, the quality of contact with family and professionals is of great importance for the overall well-being of the client (van Asselt-Goverts, Embregts, & Hendriks, 2015a). People with ID are less often satisfied with their networks than people without ID (van Asselt-Goverts et al., 2015b) and more often feel lonely (Sheppard-Jones, 2003; Valås, 1999), even up to half of them (Amado, Stancliffe, McCarron, & McCallion, 2013; Gilmore & Cuskelly, 2014; McCarron et al., 2011; Stancliffe et al., 2007).

If the networks of people with ID are small or offer insufficient support, interventions focusing on the social network are necessary. However, little is known about the effect of these interventions. Howarth, Morris, Newlin and Webber (2014) conducted a systematic review of this subject and could only include 11 studies. In six of these studies positive outcomes were found for the social participation of the person. Person-Centered Planning (PCP) (Robertson et al., 2006), alteration of activity patterns (Ouellette, Horner, & Newton, 1994) and semi-structured group programs including exercises regarding social skills (McConnell, Dalziel, Llewellyn, Laidlaw, & Hindmarsh, 2009; McGaw, Ball, & Clark, 2002; Ward, Windsor, & Atkinson, 2012) appeared to be most effective (Howarth et al., 2014). Professionals play an important role in strengthening and expanding the networks, for instance by attending to maintenance of the network, encouraging clients to call upon network members more often, discussing disturbances, involving volunteers or getting the person to participate in leisure time activities (van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014). Although it is important to strengthen and expand networks, in daily practice this appears to be difficult. Professionals mention a large number of impeding factors, such as lack of social skills of the client, a small or complex network, or falling between the cracks when it comes to leisure time (i.e. not involved deeply enough in regular leisure time activities but also not feeling comfortable with leisure time activities organized for people with ID). On the other hand, matching of interests, raising awareness and a customized approach can be seen as facilitating factors (van Asselt-Goverts et al., 2014). Training aimed at strengthening and expanding networks may be necessary and should take these impeding and facilitating factors into account.

The aim of the present study was to explore the results of a social network intervention for people with mild to borderline ID and their support staff, from different perspectives, using mixed methods in a multiple case analysis. We focused on the following research questions. What did the participants learn from the training? Were there any changes in network characteristics (i.e. size, frequency of contact, strength of the ties), satisfaction and wishes in relation to networks, participation, loneliness, self-determination or self-esteem?

6.2 Method

6.2.1 Participants

The training started with eight adults with mild to borderline ID, four men and four women. All participants received visiting support from professionals (i.e. support workers) of *Dichterbij,* an organization in the south of the Netherlands providing support for people with ID. In three cases the person or the professional could not finish the training. Eva[3] and her support worker quit after three sessions because Eva's sister died. Thomas quit after five sessions because he reunited with his ex, a woman with multiple disorders, and he decided to put all his energy into this relationship and to break ties with several of his network members, including his support workers. Anna, who got pregnant and gave birth during the study period, had to switch support worker twice and the last support worker did not join the coaching sessions.

The other five participants completed the training in collaboration with their support worker. Characteristics of these five participants are outlined in Table 1. They were supported by six professionals, two male, four female. Half of the professionals had at least 3-years professional training in social work, which is the norm in the Netherlands for direct support staff. The other three had a Bachelor degree in social work. Their age ranged from 26 to 51 years. Their work experience regarding supporting people with ID varied from 1 to 30 years.

Table 1 *Participant characteristics before training*

Participant	Age	IQ[a]			Partner	Children	Living situation	Work
		TIQ	VIQ	PIQ				
Paul	46	62	58	67	No	Yes	Alone	Volunteer/ Daytime activities
Emma	44	74	65	84	No	No	With Family	Volunteer/ Daytime activities
Rachel	38	68	60	79	Yes	No	Alone	Sheltered employment
Max	34	75	67	ns[b]	No	No	Alone	Job
Antony	35	78	87	71	Yes	Step children	With partner	Just quitted sheltered employment

[a] Dossier information, IQ measured by WAIS III in period 2002-2009; [b] Ns = not scorable due to major differences in scale scores.

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[3] For the sake of anonymity, pseudonyms are used.

6.2.2 Measures

Interviews

The participants were interviewed individually to explore their experiences and perceptions, for instance about satisfaction and wishes regarding their network and about their opinions with respect to the training. We asked them what they had learned from the training and what had changed in their lives. We conducted these interviews with the aid of an interview protocol and pictures made during the training sessions. The pictures aided recall of the different meetings. We also interviewed the participants' support workers and asked them what their clients had learned and what had changed in their lives. Finally, we interviewed the trainers to get their perspectives on the learning process of participants and support workers.

Maastricht Social Network Analysis

The shortened Maastricht Social Network Analysis for people with ID (MSNA-ID) was used to map the structural and functional characteristics of the social networks. This instrument is based on the MSNA (Baars, 1994) and adapted for people with mild ID (van Asselt-Goverts et al., 2012) and is used in research within this population (van Asselt-Goverts et al., 2013, 2015a, 2015b). In the shortened MSNA-ID, an ecogram is created to visualize the social network. Three expanding circles are placed around the name of the participant who then maps his or her relations with family, friends, neighbours, colleagues, other acquaintances and professionals by pointing to where a particular network member should be placed. The more important the network member, the closer the name is written to the name of the participant. Next, network members are listed on the MSNA-ID to map network characteristics. With this shortened version we mapped structural characteristics, namely size, frequency of contact and functional characteristics, specifically affection (e.g. feeling safe and secure with the person, loving the person), connection (e.g. liking the same things), preference (e.g. preference for contact with the person, liking the contact), and practical/informational support (e.g. being helped by the person when you don't know something or aren't able to do something). The MSNA-ID was administered before the start of the training. After the training and the coaching participants were asked whether things had changed or remained the same.

Loneliness Scale

The feelings of loneliness of the study participants were assessed with the Loneliness Scale (de Jong-Gierveld & van Tilburg, 1999), adapted for people with ID by simplifying questions (Frielink, Schuengel, & Embregts (submitted). The adapted scale consists of 11 items and answers are given on a five-point scale. For people with mild ID the internal consistency is .89 (Frielink et al., submitted) and *SD* = .63 (Frielink, Schuengel, & Embregts, in preparation).

The Basic Psychological Need Satisfaction and Frustration Scale

The Basic Psychological Need Satisfaction and Frustration Scale (BPNSFS) developed by Chen et al. (2014) is based on the self-determination theory of Ryan and Deci (2000). The adapted version for people with mild ID (Frielink et al., submitted) was used to measure feelings of autonomy, relatedness and competence. Each of the needs is operationalized in eight items, including four items with respect to need satisfaction and four with respect to need frustration. Answers are given on a five-point scale. The internal consistency of the factors autonomy, relatedness and competence are .87, .91 and .86 respectively (Frielink et al., submitted) and the *SD* = .56, .64 and .54 (Frielink et al., in preparation) for people with mild ID.

The Rosenberg Self-Esteem Scale

The Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965) was used to measure self-esteem. The RSE consists of 10 items and answers are given on a four-point scale. Internal consistency is .81 (Schmitt & Allick. 2005), but lower for people with ID: .64 (Davis, Kellett, & Beail, 2009). Therefore, Davis et al. (2009) pleaded for either the development of a new measure of self-esteem or the redesign and simplification of the RSE. For our study we adapted the Dutch translation made at Ghent University (Frank, De Raedt, Barbez, & Rosseel, 2008) for people with ID by simplifying the questions in collaboration with people with ID and their support staff.

6.2.3 Procedure

The Psychological Ethical Advisory Committee of Tilburg University as well as the scientific and ethics committee from *Dichterbij*, approved the study and one of the teams of *Dichterbij* agreed to participate in the study. This team supported 66 clients, living in their own homes or with their parents, receiving visiting support from support staff. Together with the team we selected potential participants who met the inclusion criteria, i.e. aged between 20 and 50, mild to borderline ID, absence of disturbing behaviour problems and needing for a stronger or expanded network. Ten potential participants were selected, eight of whom agreed to participate. We checked if the participants understood what the training and the study were about and told them they were allowed to stop participating in the training or study whenever they wanted. All participants provided written informed consent. The interviews were conducted at a time and place convenient to the participant. To enhance the reliability of data collection, we used an interview protocol. All interviews were conducted by the first author and were voice recorded. To increase the validity of the research we used triangulation of methods (i.e. both quantitative and qualitative methods) and triangulation of sources (i.e. interviews with participants, their support workers and the trainers). This facilitates a deeper understanding and thus rich and robust data. Interviews and questionnaires were conducted before the training (T0), after the training (T1) and after the coaching period (T2).

6.2.4 Intervention

"Die Ken Ik!" [*I know them!*], (Blommendaal & van de Lustgraaf, 2006) a semi-structured group training, was provided by a self-advocacy group. The aim of this training was to strengthen or to expand the networks of the participants with mild to borderline ID. The training was given by two experienced trainers; one of whom had mild ID himself, the other being his coach. Themes of the seven group sessions based on PCP (O'Brien, Pearpoint, & Kahn, 2010) were: (1) talents and interests; (2) network; (3) neighbourhood; (4) wishes and dreams; (5) plans for a supporters meeting (i.e. a meeting with network members to think along with the person with respect to his wishes and dreams) (6) evaluation of the supporters meeting; (7) evaluation of the training and certification (Blommendaal & van de Lustgraaf, 2006). In each session the theme of the evening was introduced, explained and discussed. Next, exercises were conducted, such as role playing and starting to make a personal map of the theme. At the end of the session homework practice was specified, generally completing the map at home. The following session started with the participants presenting their personal maps and evaluating the homework. Information about the themes was outlined in a folder, which also contained the different maps.

Because research shows that in actual practice it is hard to alter social networks (van Asselt-Goverts et al., 2014) and that professionals play an important role in the networks of people with mild ID (van Asselt-Goverts et al., 2013, 2015a, 2015b), we made some adaptations, in collaboration with trainers and support workers from the participant's team. First, the training for people with ID was combined with training for their support workers. In this way the support workers could coach their clients to make a transfer from the training to actual practice. Next, research shows that interventions aimed at changing behaviours of support staff require a training format in which in-service training was combined with on-the-job coaching (van Oorsouw, Embregts, Bosman, & Jahoda, 2009). Therefore the usual program was followed by four coaching meetings in which the support workers were coached to coach, in turn, their client. Support workers and participants with ID joined the first seven training sessions at the same time. Usually, both groups started and ended the evening together, while they were trained separately in between. The fifth and sixth sessions were an exception in this regard. In these two sessions both groups worked together the whole evening. Participants with ID made a plan for the supporters meeting in collaboration with their own support worker (fifth session) and presented and evaluated the implementation of that plan at the following session. The other training sessions for support workers contained the following elements each time: (a) theme of the evening, (b) specific competences needed to coach the participants with ID while working on this theme, (c) coaching skills and attitudes, (d) experiences of the support workers in coaching their clients working on their social networks. The seven group sessions were scheduled between March and June 2014, lasting 2.5 hours each. They were followed by four coaching sessions for support staff (September through to November 2014), based on the experiences and personal goals of the support workers regarding coaching their clients in strengthening or expanding their networks. Training of the support workers was undertaken by a trainer who was very familiar with the training methods of the self-advocacy group and experienced in the training of professionals to enhance networks.

6.2.5 Analysis

The interviews were transcribed and analyzed with the help of the ATLAS.ti (version 7.5.2). Standard content analyses based on a general inductive approach (Thomas, 2006) were conducted because our aim was to discover the experiences of the participants without prior assumptions, theories or hypotheses guiding our exploration. Decisions concerning the coding and sub-categorization were discussed among the three researchers in the research group. Quantitative data were processed and analyzed using SPSS. The MSNA-ID analyses are described in detail in a previous article (van Asselt-Goverts et al., 2013). For the Loneliness Scale and the BPNSFS-ID an average score was calculated, displayed in Table 3. To determine whether an observed change in scores was significant, we calculated a Reliable Change Index (RCI; Jacobson & Truax, 1991), if *SD* and data on internal consistency were available. Thus, for the Loneliness Scale and BPNSFS-ID, RCI calculations were conducted using the data of the studies of Frielink and colleagues. We interpreted a RCI ≥ 1.96 as a significant change, $p \leq .05$ (Jacobson & Truax, 1991). For the adapted version of the RSE no data on *SD* and internal consistency were available. RCI calculations were, therefore, not possible for the RSE. In addition to the average scores for loneliness, we also calculated, according to the manual, the sum of all items indicating a feeling of loneliness (de Jong-Gierveld & van Tilburg, 1999). This 'total loneliness score' gives an indication of the severity of the experienced loneliness and was used in the description of 6.3.2.

6.3 Results

In this section the themes that emerged from the analysis are presented: (1) increased awareness, competence and autonomy; (2) enhanced social networks and decreased loneliness; (3) increased community participation; (4) vulnerability of the participants and their networks. These themes and associated subthemes are outlined in Table 2.

Table 2 *Themes and subthemes*

Theme	Sub-themes
Increased awareness, competence and autonomy[a]	Increased awareness of themselves Increased awareness of the network Increased social skills Courage to ask others for support Increased autonomy
Enhanced social networks and decreased loneliness[b]	Network characteristics, satisfaction and wishes at T0 Positive changes in size More frequent contact Stronger ties Increased satisfaction Reduced wishes Decreased loneliness
Increased community participation[c]	Work & leisure time activities before start training Changes in work Neighbourhood contacts Increased participation in leisure time activities and education
Vulnerability of the participants and their networks[d]	Health problems Ups and downs Changes in self-esteem Conflicts in network Health problems network

[a] Measured with interviews, BPNSFS-ID competence and BPNSFS-ID autonomy; [b] Measured with MSNA-ID (T0), interviews, BPNSFS-ID relatedness and Loneliness scale; [c] Measured with interviews; [d] Measured with interviews and RSE.

6.3.1 Increased awareness, competence and autonomy: ‘I have really learned a lot’

All participants were positive about what they had learned during the training. According to interviews of both participants and the support workers, the training raised participants’ awareness of themselves, especially of their own talents (Paul, Emma, Max, Anthony). In the words of Emma:

> *What have I learned? Basically, I have learned more about myself. To think about myself more consciously. (Emma, T1)*

Next, the training raised awareness of the importance of network members to all participants. For instance, Anthony and Rachel said that the training had made them realize who their real friends were and Paul’s support worker said that Paul realized that he himself had to invest in his contacts.

Table 3 shows scores on autonomy and competence. Three participants experienced significantly more feelings of competence after the training (Paul, Max, Anthony). In the interviews participants explained what they had actually learned: dare to make contact and chat more easily with people (Paul, Emma, Rachel, Max). For instance, Paul said about his gained competences:

> *I'm talking more now … since the training. Haven't you noticed? (laughs). I now talk more easily. ... At first I always stayed silent … and I waited until people started talking to me, but now I actually start a conversation myself. (Paul, T1)*

Moreover, due to the training participants became more able to ask others for support (Rachel, Anthony). Anthony got affirmation in his supporters' meeting that he can always call on his father-in-law to discuss things and, since then, Anthony has made use of this offer. Rachel's supporters' meeting also played a crucial role. According to her support worker, Rachel interacted with people less familiar to her during the supporters' meeting and, due to this positive experience, she became less afraid to ask people for help. This is in line with Rachel's answer to the question of what she had learned during the training:

> *How best to make contact. It does not always have to be about the same subject (silence). And also how you go about arranging things. You do not always have to do everything yourself. You can always ask people. (Rachel, T1)*

Finally, significant changes in autonomy were noted for all of the participants, except Rachel, who already scored high on autonomy before the start of the training (Table 3). For instance, Emma made significant progress in autonomy. This was in line with her remark that her support workers let her do and decide things more by herself and her support worker's view that she had learned to do more things by herself and had become clearer in telling her sisters and support workers what is important for her. The progress made by Max was also noted by his support worker, who said in the interview at T2 that Max stands up more for himself in contacts with his network members.

6.3.2 Enhanced social networks and decreased loneliness: ‘I am not lonely anymore’

At T0, the network size of the participants ranged from 11-34 network members among which were 2-21 acquaintances (i.e. friends, neighbours, colleagues and other acquaintances). Table 4 provides detailed information about size, frequency of contact and functional characteristics of the participants at T0. Four of the participants said they were satisfied with their network. However, all of them indicated several wishes for their network at that moment: (a) an expansion of the network (Paul, Emma, Rachel, Max); (b) finding a partner (Paul); (c) meet network members more frequently (Paul, Rachel); (d) more insight into which members are really important (Anthony); (e) improve social skills to make and maintain contacts (Paul, Max, Anthony); or (f) wishes regarding more qualitative aspects of the ties (Emma, Rachel, Anthony). These latter wishes included that others take more initiative (Emma, Rachel), more confidence in others and less interference from her sisters (Emma), and patch up a conflict between family members (Anthony). Other wishes were related to changes in the care system: the hope that support workers were able to maintain their support (Emma, Anthony).

At T1 and T2 participants were asked whether there were any changes in size, frequency, and strengths of their ties. There had been changes in the networks of all participants. However, *what* changed differed, in line with their wishes before the training. With respect to network size, three participants said that they had more people on their ecogram at T1 en T2 than at T0 (Paul, Emma, Rachel). For instance, Paul and Emma got into a relationship with each other and they both put each other and their family-in-law on the ecogram. Other new network members were colleagues (Paul, Emma, Rachel), participants in the training (Rachel) and other acquaintances (Emma). Besides this expansion shown in the ecogram, both Paul and Max said that they were chatting more often and to more people, who were not on their ecogram, for instance with a neighbour, an acquaintance or a cashier:

> *In fact, during the training I looked around more ... what more could I do to get to know more people. ... I do go to a supermarket regularly and there I chat to people. Even people that I often see at the checkout. I quite often chat with them. (Max, T1)*

Table 3 *Autonomy, competence, relatedness, loneliness and self-esteem at T0, T1 and T2*

Participant	Autonomy			Competence			Relatedness			Loneliness[a]			Self-esteem		
	T0	T1	T2	T0	T1	T2	T0	T1	T2	T0	T1	T2	T0	T1[e]	T2[e]
Paul	3.0	3.1	4.0[c,d]	1.5	2.9[b]	3.9[c,d]	3.6	5.0[b]	4.8[d]	1.6	4.4[b]	4.7[d]	7	19	23
Emma	2.6	3.0	3.8[c,d]	2.9	2.9	2.5	3.8	3.9	4.0	2.8	3.8[b]	3.6[d]	11	14	13
Rachel	4.0	4.0	4.0	4.3	4.1	4.4	4.4	4.1	4.3	3.6	4.5[b]	4.6[d]	18	24	22
Max	3.5	4.3[b]	4.6[d]	4.0	4.4	4.9[d]	4.3	4.5	4.5	2.6	3.6[b]	4.4[c,d]	24	27	25
Anthony	3.4	3.9	4.3[d]	3.5	4.4[b]	4.1[d]	4.8	4.8	5.0	4.8	4.9	4.7	21	26	24

[a] Higher scores reflect less loneliness; [b] T1-T0 significant difference; [c] T2-T1 significant difference; [d] T2-T0 significant difference; [e] No RCI calculations possible.

Table 4 *Size of the network, frequency of the contact and functional characteristics of the networks at T0 (MSNA-ID)*

Participant	Size						Frequency[a]			Functional Characteristics[b]			
	Family	Acquaintances				Prof							
		Friends	Colleagues	Neighbours	Others		F-t-F[c]	Phone	Internet	Affection	Connection	Preference	Practical/ Informational
Paul	5	1	2	0	0	3	ns[d]	ns[d]	0.0	4.5	4.7	4.7	4.8
Emma	9	1	0	0	1	4	114.4	53.7	57.3	4.4	2.6	3.9	3.9
Rachel	8	5	2	0	3	1	88.0	13.3	7.8	4.1	3.6	3.9	2.3
Max	3	3	0	2	1	7	120.9	68.7	17.0	4.5	4.2	4.7	4.7
Anthony	12	4	0	3	14	1	68.9	63.6	6.4	4.7	3.9	4.5	4.8

[a] Times a year. Mean; [b] Means along a five-point-scale; [c] Face to face contact; [d] Not scorable: question is too difficult, due to his memory disorder by acquired brain injury.

For Anthony a decrease in network size was noted. At T1 he no longer had 21 acquaintances on his ecogram. According to Anthony, this was a positive change because he now knew who his real friends were. Moreover, the quality of his relationships improved. For instance, the tie with his father-in-law was strengthened due to the supporters' meeting. This was because they had talked about Anthony and his impulsiveness in this meeting, and as a result his network members knew how to deal with him better afterwards and Anthony got the affirmation that he can always call on his father-in-law to discuss things. Also the other participants experienced benefits to the quality of their ties from the supporters meeting (Paul, Emma, Max). For instance, after things were talked over in Paul's meeting, he was reassured that his parents will always be there for him. Indeed, at T1 he said that he had contact with his network members more often and experienced a stronger tie to them. Also Emma's sister understood Emma's situation better after her supporters' meeting:

> *This week my sister ... sent a message: 'How are you doing? I haven't heard from you for a while'... And she would not have done that so quickly before. (Emma, T2)*

As a result of these positive changes in their networks, some of the participants were more satisfied at T1 and T2 (Paul, Rachel, Max), having fewer or no network wishes left. Other wishes, however, remained at T1 and T2. Participants desired to have more confidence in others, network members to patch up conflicts, and to maintain contact with support workers despite changes in the care system.

In addition, as a result of the enhanced networks, changes in relatedness were observed for Paul during the training (Table 3). This did not hold for the other participants, whose scores were already high before the start. The Loneliness Scale, however, differentiated more. At T0 four participants experienced moderate (Emma, Rachel) to severe loneliness (Paul, Max), based on their sum scores on the Loneliness Scale. This is in line with the remark of Paul's support worker at T0 that Paul often told her he was very lonely and the statement of Max at T0 that he was a 'loner'. Table 3 shows that the scores on loneliness improved significantly for all participants who were lonely before the start. None of the participants perceived to be lonely afterwards.

6.3.3 Increased community participation: 'Now I get around more'

At T0 all participants except Anthony had work, day activities or volunteer work during the day (Table 1). Anthony was on sick leave, and was going to quit his work at the sheltered work place and look for volunteer work. Paul and Rachel experienced changes in work during the training period. Paul tried all kind of jobs, Rachel changed work location. The interviews also gave insight into the leisure time activities of the participants. Some participants were members of leisure clubs: water basketball (Rachel and Max), a computer club (Max), or a billiard club (Anthony). Contact with neighbours was restricted to a greeting and short chats, and that was sufficient for them. In the words of Rachel:

> *Because I have almost no contacts here* [*in the neighbourhood*] *and I don't want any. I had some when I lived at* [*old address*], *but here I would rather not have any. There I attracted the wrong sort of people. Here in fact, I do talk to people in the neighbourhood, but I would hesitate to invite them to visit me. (Rachel, T1)*

After the training, participation in leisure activities and education increased, in accordance with the wishes expressed in one of the training sessions and discussed in the supporters' meeting. Rachel planned an evening with family and friends; she taught them to Fun Loom and they went out for a dinner. Max went on a weekend trip on his own for the first time in his life, to meet new people. Moreover at T2, he started to paint his house to make it tidy in order to invite people over and he went out more often. He quit his computer course and water basketball temporarily to have more time for himself, and to care for his family and his house. His professional added that he insisted on not quitting his activities permanently, so as not to reduce his network and suggested that he asked network members to help him with his house. But Max had chosen to do this on his own to show people that it was within his capabilities. Moreover, due to the training Anthony was inspired to follow the training 'expert by experience', in which people with ID learn to reflect on their own experiences and how to use these in supporting others. Finally, Emma and Paul attended a course in English. Paul said he was more active than before:

> [*I go*] *to the market, and the village (laughs). Actually, all sorts of things, walking the* [*Emma's*] *dog, visiting family. (Paul, T2)*

6.3.4 Vulnerability of the participants and their networks: 'Ups and downs'

All participants appeared to have a turbulent life in terms of health problems, life events, ups and downs and worries. Four participants experienced severe health problems: epilepsy (Rachel); memory disorder due to brain injury (Paul - in 1989); physical problems (Paul, Emma, Rachel, Anthony); needing treatment from a rehabilitation centre (Emma, Anthony) or mental health problems (Paul). Several participants had to deal with major life events: getting a partner (Paul, Emma) and changing job (Paul, Rachel). The participants (especially Paul, Emma, Max), experienced ups and downs in their lives according to their support workers. This can be illustrated by Paul's story, as told by his professional. Before the training Paul often told her he was very lonely and did not know what he liked or what he could do and had little confidence in himself. At the start of the training there was a period of severe anxiety for which treatment from a mental health agency was necessary. Later he felt better and better and gained self-confidence. This positive development was reflected in a positive change of his scores (Table 3), in particular on competence, relatedness, self- esteem and loneliness. Subsequently his professional noted a negative change in self-esteem. Changes in work activities and the expanded network, with Emma and her family brought anxiety and stress: more people, more expectations. Also his girlfriend Emma had her ups and downs, due to their relationship, her extended network and worries. According to her support workers this caused changes in self-esteem, but was also inherent to this new stage of life, with new incentives for Emma. The trainer of the support workers concluded:

> *And this is a learning process that occurs in alternating periods, I think, of crisis, growth, crisis, growth. Through awareness you can, on the one hand, get growth, but also crisis. So a key competency is to coach a person in his growth curve. (Trainer, T2)*

Looking to the RSE (Table 3), self-esteem of the participants appeared to improve during the training. But for four participants it seemed hard to maintain these improvements over the course of the coaching period, although the scores after this period still seemed higher than before training. At T1 Anthony said he felt 'lifted up' by the training, using the word 'proud' nine times. He said, for example, about the effect of the talent map:

> *Yes, I was very proud. I really thought, look at where I am now, you know. This is me. I'm allowed to be here. I'm not ... someone with a disability who cannot do things. No, I am who I am and I am accepted and I'm proud of ... what my talents are. (Anthony T1)*

In Anthony's network there were several escalations during this period. Anthony struggles, in particular, with the conflict between his sister and his parents. Also the conflict between Emma's twin sister and her oldest sister had great impact on Emma's life:

> *Emma feels caught between them. At the moment, she chooses her* [*twin*] *sister, with whom she lives, because, she says: 'I live with her, so I choose her'. (Support Worker Emma, T0).*

Family members of three participants had severe health problems (Emma, Max, Anthony). For instance, two of Emma's sisters had health problems and the condition of her incurably ill twin sister worsened. Max's brother had ADHD, PPD-NOS, anxiety disorders and muscle disease and suffered from kidney stones. Max had to take him to the hospital several times, even during the night. The ups and downs of the participants were partly related to these health problems and conflicts in their networks.

6.4 Discussion

This multiple case analysis was aimed at exploring the results of a social network intervention in the lives of people with mild to borderline ID. The analyses revealed several benefits of the social network intervention. The participants gained awareness of themselves and their network, which can be seen as a facilitating factor in enhancing social networks (van Asselt-Goverts et al., 2014). In addition, they gained competences. Some of them learned social skills, others overcame their shyness to ask others for help. Linders (2010) introduced the terms 'shyness to ask for help' and 'hesitation to offer unsolicited help' as an explanation for situations where informal care is not achieved. The so called 'supporters meeting', used as part of the training, appeared to be a good means to tackle this problem. Moreover, significant changes in autonomy were noted, in line with previous PCP research showing a change in the area of choice (Robertson et al., 2006; Claes, van Hove, Vandevelde, van Loon, Schalock, 2010). In our study the changes in autonomy occurred mainly during the coaching period, which emphasized the importance of this added coaching. Most remarkable was the significant decrease in loneliness, which could be related to more frequent contact with network members, improvement of quality of contacts or an expansion of the network or chatting to more people outside of the regular network. These positive changes in social networks and the increase in community participation are in line with the positive results in other PCP research (Claes et al., 2010; Robertson et al., 2006). The story of Anthony shows that more network members is not always better. Indeed, size is not a decisive factor for well-being and network interventions should always be customised to the opinions of the person involved (van Asselt-Goverts et al., 2015a, 2015b). The stories of Max and Paul show that it is important to say "hi", to and have short chats with neighbours, cashiers and other acquaintances. The importance of these fleeting and superficial contacts has been emphasized in previous studies (Bredewold, Tonkens, & Trappenburg, 2014). Further, the other participants did not want more profound contact with their neighbours, preferring an appropriate distance, as is usual between neighbours (Bredewold et al., 2014). The story of Paul illustrates the importance of having a relationship for well-being, which is well-known from the literature (Arias, Ovejero, & Morentin, 2009; Lafferty, McConkey, & Taggart, 2013). His major progress might be attributable to getting into a relationship, which makes the progress vulnerable. If the relationship does not work out and breaks up, he might be back to square one. Having a partner and an extended network also raises new support needs. As a result, the role of the professional changes (i.e. focusing on people in their network), but their role does not disappear. Enhanced networks are not a substitute for professional support. Indeed, the vulnerability of people with ID (e.g. ups and downs due to worries, changes and life events) and the vulnerability of their networks (e.g. health problems, family conflicts) calls for support workers who keep in touch. It also calls for support workers who are able to attune the level of support to these changing needs and to pay attention to enhancing self-esteem.

The chosen methodology has strengths and some possible limitations. The focus was on adults with mild ID without behaviour problems, which means that the results cannot be generalized to other target groups. People with ID as well as behaviour problems have fewer social skills (Kearney & Healy, 2011) and are more likely to experience negative social interactions (Lunsky & Havercamp, 1999) than those without behaviour problems. It is, therefore, recommended that future research examines to what extent people with a dual diagnosis benefit from such a network intervention. In addition, other variables may interfere with the results of the intervention, such as the life events mentioned before and the Hawthorne effect, i.e. the influence of participation in research on the results. Being asked about one's opinions might affect, for instance, self-esteem. Next, in this study we focused on individual and interpersonal variables. Future research should pay attention to other factors, for instance the influence of community conditions, such as availability and access to services, neighbourhood characteristics and attitudes of community members (Simplican et al., 2015; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014; Pelleboer-Gunnink, van Weeghel, & Embregts, 2014). In addition, the training was designed as a unit, including coaching for both participants and their support staff. Effects or impact of these different components are inherently difficult to distinguish. Owing to these factors and the largely qualitative and small-scale design of this study, without a control group, generalizing our findings or concluding that this is an evidence based training is restricted. However, the different points of view (i.e. participants, support workers and trainers) and different measures (i.e. open interviews and questionnaires) used provided a richer and in-depth understanding of the complexity of an intervention study in a social context than studies with a large scale design might. The overall findings of this case series provides 'indicative evidence' for the effectiveness of this intervention (Veerman & van Yperen, 2007). These findings are promising and justify a larger series of case studies or a larger control trial study of this intervention.

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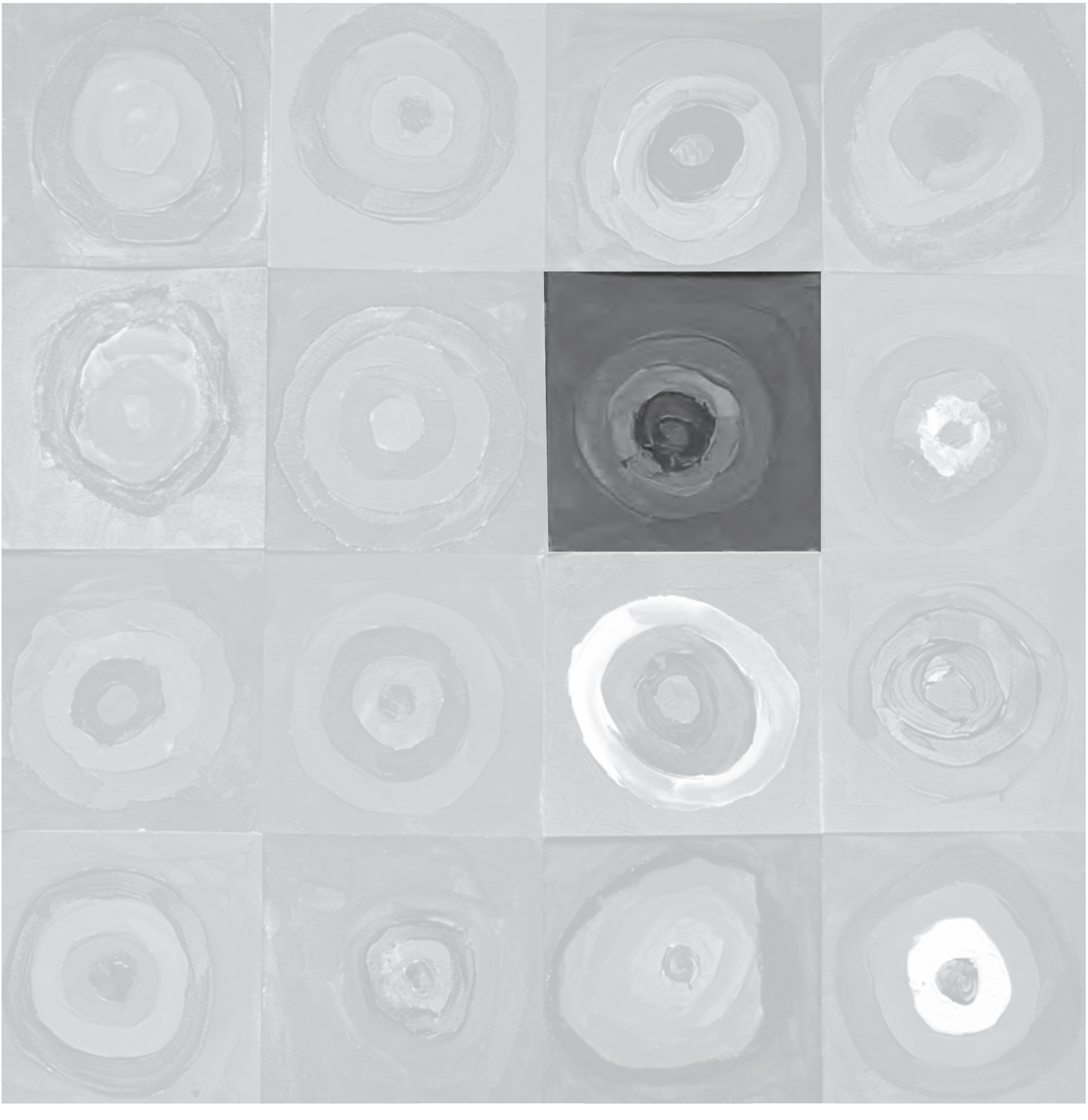

Chapter 7

General discussion

7.1 The present thesis

Support for people with ID has greatly changed over the past decades. The concept of QOL has been introduced into the care of people with ID and is now widely used to evaluate their general well-being. Social inclusion is seen as an important domain of QOL. Social inclusion focuses on two domains, social relationships and community participation (Simplican, Leader, Kosciulek, & Leahy, 2015). Nowadays, more and more people with ID live in the community, with the goal of increasing social participating and receiving support primarily from their family, friends and neighbours. However, people with mild ID increasingly apply for professional support (Ras, Verbeek-Oudijk, & Eggink, 2013). This appears to be related to the increased complexity of society today, the growing expectation that people with ID will play a full part in society, and a lack of adequate social networks (Woittiez, Putman, Eggink, & Ras, 2014). Social networks are crucial in helping people with mild ID to cope with this more complex society and these growing expectations to participate and thereby enhance their well-being.

However, a comprehensive picture of the structural and functional characteristics of the networks of people with mild ID from their own perspective is still lacking. In addition, research into the experiences of people with mild ID and their support workers with network interventions and the effect of these interventions is also scarce. Therefore this thesis had two aims: (a) to provide a comprehensive picture of the specific characteristics of the networks of people with mild ID from their own perspective; and (b) to gain insight into network interventions and how well they succeed. The thesis consisted of two parts. The first part contained three chapters (chapters 2, 3 and 4) and was focused on the network characteristics from the perspective of people with mild ID themselves. In the second part of the thesis we focused on network interventions from the perspectives of both persons with ID and their support workers (chapters 5 and 6). In this final chapter the main findings of the thesis are summarized, and the strengths, limitations and implications for future research, policy, practice and education are discussed.

7.2 Main findings

The first part of this thesis focused on the network characteristics and network perceptions of people with mild ID. A comprehensive examination of both the structural and functional characteristics of the social networks of 33 people with mild intellectual disabilities was provided alone as well as in comparison with people with Autism Spectrum Disorders (ASD) and a reference group of other people living in the community. First, with respect to the structural characteristics, the social networks of the individuals, who all lived in the community, varied from four to 28 members (*Mean* 14.2); 42.7% of the network members were family members, 32.8% acquaintances (i.e friends, colleagues, neighbours, other acquaintances) and 24.5% professionals (chapter 2). People with ID and people with ASD had less network members on their ecograms compared to the reference group, showing that their networks are more restricted (chapter 4). This is in line with previous research showing that the networks of people with ID are generally small (e.g. Lippold & Burns, 2009; Robertson et al., 2001; Verdonschot et al., 2009). The measures used are of importance in calculating the size of a social network. Due to its comprehensiveness, the MSNA seems to measure the quality of the most important relationships more than the actual size of the network, especially if networks are large. In comparison with other members of their community, people with ID have known their acquaintances for a shorter duration and see them more often. Moreover, they considered that the initiation of the contact was less often reciprocal than people from the reference group. Instead they considered themselves to be the main initiator of contact more often (chapter 4). Next, findings on functional characteristics indicated that people with mild ID assigned relatively low scores to the connection characteristic of the social networks and assigned high scores to professionals for affection and practical support (chapter 2). People with ID felt greater affection for their professional network members compared to the reference group (chapter 4). The participants' perceived QOL positively related most to these functional characteristics, which is in line with the findings of previous research showing an association between perceived support and subjective QOL (Bramston, Chipuer, & Pretty, 2005; Lunsky & Benson, 2001; Miller & Chan, 2008; Stenfert Kroese, Hussein, Clifford, & Ahmed, 2002). Our results provided a more detailed insight into the perceived support and show affection – especially towards family and professionals – relates most strongly to perceived QOL (chapter 3). With respect to size of network, the number of acquaintances was seen as important. For the other characteristics of the network, family seemed crucial. It appeared to be essential that relatives live in the same town, were able to meet up frequently and provided both emotional and practical support (chapter 3). Moreover, with respect to the perceptions of the networks, the majority of the participants (73.1%) were satisfied with their social networks (chapter 3). People with ID or ASD were less often satisfied with their network and more often neutral than the reference group (chapter 4).

In the second part of the thesis we focused on network interventions and how well they succeed. In the studies previously referred to we found that the role of professionals in the networks was important. We therefore focussed, in chapter 5, on the perspective of support staff and their experiences with network interventions aimed at strengthening and expanding the social networks of people with mild ID. The results showed interventions to strengthen social networks (e.g. attention to the maintenance of contact with network members) and interventions to expand social networks (e.g. participation in leisure time activities and working with volunteers). However, a large number of impeding factors were mentioned by support staff, such as the limited size of the social networks, characteristics of the client, different perceptions and clients falling between the cracks when it comes to leisure time. Facilitating factors were also mentioned, such as making use of a plan, matching of interests, awareness and a customized, individualized approach. However, the large number of impeding factors shows that strengthening and expansion of social is complicated in actual practice.

Finally, we conducted an intervention study, described in chapter 6, based on the findings of chapter 5. An intervention fitting with the aforementioned facilitating factors was *'Die Ken Ik!'* [*I know them!*] (Blommendaal & van de Lustgraaf, 2006), a semi-structured group training for people with mild ID, offered by a self-advocacy group. Moreover, the themes of this intervention were based on Person Centered Planning (PCP) (O'Brien, Pearpoint, & Kahn, 2010), an internationally well-known intervention, with positive outcomes on social participation (Howarth, Morris, Newlin, & Webber, 2014; Robertson et al., 2006). We made some adaptations to the training in collaboration with trainers and support workers, based on the finding that professionals play an important role in the networks of people with mild ID (chapters 2, 3, 4 and 5) and that in actual practise it is hard to alter social networks (chapter 5). In this way we combined the group training for clients with mild ID with training for their professionals and added coaching sessions. We conducted a multiple case-analysis to examine the results of this intervention in the lives of people with ID. Although participants and their networks appear to be vulnerable, the findings were promising and in line with former PCP research (Claes, van Hove, Vandevelde, van Loon, & Schalock, 2010; Robertson et al., 2006). For instance, the participants felt more aware of themselves and their network, they learned to make contact and to ask for help and felt more autonomous. Moreover, they experienced an enhancement of their networks, a decrease in loneliness and an increase in community participation. The overall findings show an indicative level of evidence (Veerman & van Yperen, 2007) for the effectiveness of the intervention (chapter 6).

7.3 Qualifications of thesis: strengths and limitations

This thesis has methodological strengths and limitations. Each chapter deals with its specific limitations. In this general discussion we address several general strengths and limitations, related to choices with respect to participants, measures, sample size, inclusion criteria and the level of interventions.

The strength of our thesis is the main focus on the perspective of persons with ID. Persons with ID should be asked about their own views (Roeleveld, Embregts, Hendriks, & van den Bogaard, 2011; Verdugo, Schalock, Keith, & Stancliffe, 2005) because they are the experts on their own feelings and experiences and thus on their own opinions (Cambridge & Forrester-Jones, 2003; Forrester-Jones et al., 2006). Research has also shown people with mild ID to be reliable reporters of social support (Lunsky & Benson, 1997). The perspective of persons with ID was examined in chapters 2, 3 and 4, while the perspective of the professional was examined in chapter 5. Moreover, in chapter 6 we combined both points of view in our intervention study. Another strength is the mixed methods methodology in our research. We made use of both quantitative and qualitative techniques, including questionnaires, open interviews, group interviews, and pictures. This provided an in-depth understanding of the complexity of network interventions in a social context. An approach using multiple sources of information is considered to provide the most accurate and comprehensive picture of social inclusion (Amado, Stancliffe, McCarron, & McCallion, 2013).

However, self-report measures can also affect the reliability of the results. We tried to increase the reliability of self-reports by simplifying the questions and by using visualization (e.g. ecograms, pictures), by avoiding suggestive questions and avoiding judgements. Nevertheless, it is possible that, for some of the participants, some questions were difficult (e.g. too abstract), especially in chapter 3 regarding satisfaction and wishes. A lack of knowledge or experience might explain why participants did not mention the wish to expand their networks, even though their networks were not very large (chapter 3). Moreover, under relatively stable but diverse living conditions, most people feel satisfied with their lives (Cummins, 1995). Nevertheless, the satisfaction measure did differentiate between the three groups in chapter 4, showing people with ASD and ID being less often satisfied than the reference group. Given these considerations, we added a loneliness measure to our intervention study (chapter 6) and combined the perspective of the person with ID with the perspective of the professional.

In our thesis the MSNA (Baars, 1994) was used to map the social network characteristics (chapters 2, 3, 4 and 6). The MSNA has been used with different research populations, including people with psychiatric problems (Baars, 1994), fibromyalgia patients (Bolwijn, van Santen-Hoeufft, Baars, Kaplan, & van der Linden, 1996) and Kenyan street children (Ayuku, Kaplan, Baars, & de Vries, 2004). We adapted the measure for people with ID (van Asselt-Goverts et al., 2012) by simplifying the questions and using visualization. This adapted version of the MSNA appeared to be a useful instrument for systematically mapping the social networks of people with mild ID because it gave a large amount of information on both the structural and functional characteristics of the social networks from their own perspective. However, the MSNA does not focus specifically on stressful characteristics of the network members, such as conflicts or behavioural problems in network members. As such, network members can have a harmful rather than a beneficial influence (Lunsky & Havercamp, 1999). Moreover, the MSNA measures reciprocity of the initiation of contact, not the reciprocity of the support, which is a key factor for the maintenance of supportive relationships over time (Biegel, Tracy, & Corvo, 1994; Ferlander, 2007; Lunsky, 2006).

Our findings were based on a small sample and generalization of the findings is therefore restricted. In addition, the focus of this thesis was on adults with mild to borderline ID, living independently in the community. Thus, the findings cannot be generalized to other target groups such as people in a different age category or people with a different level of ID, people living in group homes or with their parents, or ID people with behaviour problems. Moreover, our thesis focused on the individual networks of persons with mild to borderline ID, their personal wishes and interventions at micro level; we did not investigate interventions at the meso and macro level. In other words, we did not examine the role of organisation and the role of the wider community that can help and hinder the development and maintenance of social networks via attitudes and the acceptance or rejection of people with ID (Pelleboer-Gunnink, van Weeghel, & Embregts, 2014).

7.4 Future research

Future research based on the findings of this thesis and the reflection on the strengths and limitations is needed. First, in this thesis the focus was on people with mild ID themselves and it was their opinions that were explored. We involved people with ID in the pilot phase to adapt measures. We also collaborated with an experienced trainer with mild ID from a self-advocacy group together with his coach (chapter 6). The value that this added to the training was very evident. For instance, this trainer explained things clearly, was in tune with the participants, and was a role model for one of the participants, who made plans to attend a training for 'experts by experience' himself. We recommend the involvement of people with ID in future research, in line with the studies of O'Brien, McConkey and García-Iriarte (2014) and Puyalto, Pallisera, Fullana and Vilà (2015). These 'experts by experience' will be involved as co-researchers in future research (Balkom et al., 2014; ZonMw, 2015) and to facilitate this, a so called 'breeding ground of experts by experience' will be created based on the research of Embregts et al. (2015). This group of experts will work on the competencies of 'experts by experience', their coaches and researchers. Moreover, at the HAN University of Applied Sciences research has been started on a collaboration between students and people with mild ID as co-researchers (van Asselt-Goverts, Heessels, Slagboom, Prudon, Biene, Hermsen). We have found that it is important to have a coach support these co-researchers. In a new study at the HAN University of Applied Sciences the role of the coach is being investigated, considering what knowledge, skills and attitudes are needed to coach people with mild ID to participate in research, practice and education (Hees, van Oostaijen, van Asselt-Goverts, Hermsen).

Next, we recommend that some of the studies are repeated with a larger sample size. This holds for the studies in chapters 2, 3 and 4, but in particular for the intervention study. The findings in this study, described in chapter 6, were promising and justify a larger series of case studies or a larger control trial study of this intervention. This study showed the value of measuring loneliness (along with satisfaction and wishes for participant's social networks), autonomy and competence. We recommend to use such measures in future research on social networks and network interventions. In a current study (Frielink, Schuengel & Embregts, submitted) validation of these instruments has been conducted. In addition, based on the finding (chapter 6) that networks can be vulnerable, attention should be paid to negative aspects of social networks, such as conflicts. Reciprocity (e.g. mutual feelings and mutual support) is also recommended as a topic for future studies because it is a key factor for the maintenance of supportive relationships over time (Biegel et al., 1994; Ferlander, 2007; Lunsky, 2006). The importance shown of having a family (chapter 3) and having an intimate relationship (chapters 5 and 6) calls for further exploration of these themes. Recently started research at Tilburg University (Giesbers, Embregts, Hendriks, Hastings, & Jahoda) focuses on family networks and includes the topic of reciprocity. Attention should also be paid to the social networks of individuals with moderate and severe ID because these people are rarely considered in the participation literature (Verdonschot et al., 2009). At the University of Groningen research is being conducted on the social networks of people with profound intellectual and multiple disabilities (Kamstra, Putten, Post, & Vlaskamp, 2014; Kamstra, Putten, & Vlaskamp, 2014). Research on the social networks of people with mild ID and behaviour problems is also scarce and particularly recommended because of the increased prevalence of these problems in people with mild ID (Emerson, 2003). The specific characteristics of their networks are going to be explored in research at Tilburg University (Tournier, Embregts, Hendriks, Jahoda, & Hastings). Future research should also focus on interventions that can enhance the networks of people with ID and behavioural problems. What are the experiences of support staff in enhancing clients' networks? Do they benefit from social network training and, if so, to what extent and in what way?

Finally, there is a need for a more thorough investigation of interventions at the meso and macro levels. This includes the role professionals as a bridge to the wider community. These professionals would also be good candidates to teach community members to be more sensitive to the needs of individuals with ID. This would contribute to a change in attitudes and motivation of the community to provide a positive welcome for people with ID in the community (Abbott & McConkey, 2006; Lunsky, 2006). This also includes the role of organizations in facilitating people to think beyond the level of the single individual or single organization (Schalock, Verdugo, Bonham, Fantova, & van Loon, 2008). Moreover, this includes research on the influence of community conditions, such as availability of and access to services, neighbourhood characteristics and the attitudes of community members (Overmars-Marx, Thomése, Verdonschot, & Meininger 2014). The required investigations also include research on attitudes, acceptance, rejection and stigma in the community. Anti-stigma and anti-discrimination strategies have been proposed as tools to improve social inclusion (Cobigo & Stuart, 2010; Pelleboer-Gunnink et al., 2014). High quality research on these themes is limited (Scior, 2011) but research on attitudes and stigma has recently been started at Tilburg University (Pelleboer-Gunnink, Habraken, van Weeghel, & Embregts).

7.5 Implications for policy, practice and education

In this paragraph we make some recommendations for policy and practice. What lessons can be learned from the findings in this thesis for policy makers, for people with mild ID, for their support workers in their daily practice and for the training and education of future support workers?

In the policy and practice related to the networks of people with ID, the main focus is often on the size of networks. Although it is useful to consider size, this thesis emphasizes that people can have different opinions regarding what is the best size for a network. A larger network is not necessarily better (chapter 6) and the number of network members is not a decisive factor in well-being (Lippold & Burns, 2009). In policy and practice it may be effective to give more attention to more qualitative aspects of social networks, including crucial structural and functional network characteristics ranging from the frequency of social contacts to practical and emotional support (Baars, 1994), network opinions and perceived loneliness. In addition, in line with Bredewold, Tonkens and Trappenburg (2014), chapter 6 highlights the importance of fleeting and superficial contacts with neighbours, cashiers and other acquaintances. The value of these contacts should not be underestimated by support staff and policy makers.

It is recommended that social networks be systematically mapped using an instrument such as an ecogram or the MSNA (Baars, 1994; van Asselt-Goverts et al. 2012). The use of an instrument to measure satisfaction and wishes is also recommended. However, it is important that support staff realize that these measures have their limitations. People can be satisfied, regardless of the negative conditions they experience (Nota, Soresi, & Perry, 2006). Just because someone reports being satisfied does not mean that they are socially connected. Also our intervention study (chapter 6) showed that people who said that they were very satisfied with their networks were sometimes very lonely and had multiple wishes for their network. Thus, even if people say that they are satisfied with their network, it is appropriate to continue to ask questions regarding loneliness or network wishes. However, people who do not have experience in making new friends may not be aware of the fact they could and may not even wish to have more friends. It could therefore be helpful to give some options. People could be asked whether they have any wishes for their network. For instance, would they like to see people more often, to have better contact with network members, to do other things with network members or to meet new network members? It may also be necessary to add a loneliness questionnaire. Although measures of satisfaction and wishes can have limitations, in actual practice it is considered useful to assess the opinions of clients with respect to their social networks. It is necessary that support workers and policy makers realize that mapping social networks is not an end in itself, but is always a means. It can be supporting in conversations with the client about their network opinions and wishes and it can be a way to tailor network interventions to the strengths and limitations of the networks.

This thesis shows the important role of support workers in the networks of people with mild ID. They are highly valued by people with mild ID with respect to several functional characteristics (chapters 2 and 4) and the quality of the contact with them is of great importance for the overall well-being of the client (chapter 3). The implication of these findings for policy makers is that reducing support or changing a support worker can have a great impact on the well-being of a person with mild ID. It would also be useful for support staff themselves to recognize their importance so that, if it is still decided to reduce support to a person with mild ID, the implications can be discussed clearly with the client so that he or she can work on meeting his or her needs for affection, connection, and practical/informational support via their informal network (i.e., family, friends, colleagues, neighbours and other acquaintances). The so-called 'supporters meeting' (i.e., meeting with network members to think along with the person with respect to their wishes and dreams) can be a good means to strengthen ties with these informal network members and to call upon them more often (chapter 6). We therefore recommend that support staff encourage their clients to invite people who are important or involved to think along with them in a 'supporters meeting' or in a regular conversation with their support worker. People with mild ID had a high frequency of contact with network members (chapters 2 and 4). Professionals can avoid overburdening the social network (Oudijk, de Boer, Woittiez, Timmermans, & de Klerk, 2010) by adopting interventions aimed at expanding and improving the individual's social network (chapter 5), rather than simply increasing the frequency of contact. Moreover, the need for connection on the part of the participants was perceived, in our study, to not be well met (chapter 2 and 4). People with mild ID have — just as other people do — a need to belong, to find support and to connect with others on the basis of shared interests, values and backgrounds (Baars, 1994). To promote such a connection, it is therefore recommended that greater attention be paid by support workers to the interests of the client and greater effort be expended to bring people with similar interests together (Lunsky, 2006), which is a facilitating factor in social inclusion (chapter 5).

The expectations in current policy of the role of the informal network and the participation and inclusion of people with mild ID are high. To facilitate social inclusion training of people with ID and support staff might be useful. The training studied in chapter 6 was promising and several benefits were noted (e.g. enhanced network, decreased loneliness, increased autonomy, competence and community participation). However, the vulnerability of the participants (e.g. ups and downs due to worries and changes) and their networks (e.g. health problems, family conflicts) were noted. We also found that having an extended network raised new support needs. Ongoing coaching was required to provide the necessary support. Thus, enhanced informal networks are not a substitute for professional support, because of the possible vulnerability of this informal network and because of the nature of these ties. Indeed, contacts with informal network members should not be rigid or unidirectional and the creation of a care-related relationship of dependency should be avoided (van Alphen et al., 2009). Instead, it is crucial to recognize the members of a client's social network as private individuals and not as unpaid professionals who can be expected to tackle things in a methodical manner (van Heijst, 2008). Informal network members should not be construed as a cheap source of support in times of cutbacks but, rather, as a valuable resource in light of people's need for connection and belonging (Kersh, Corona, & Siperstein, 2013). As a result, with enhanced networks the role of the support worker does not disappear, but it does change. In this new role support workers will be able to combine high quality interpersonal relations with their clients (Embregts, 2009, 2011; Hermsen et al., 2014; Machielse & Runia, 2013) with competences in coaching them to enhance their networks. This new role calls for support workers who keep in touch and who can tune the level of support to the changing needs of their client and their networks. It calls for support workers who are able to include the perspectives of their clients and their network members, involve these network members and meet needs to strengthen and expand networks.

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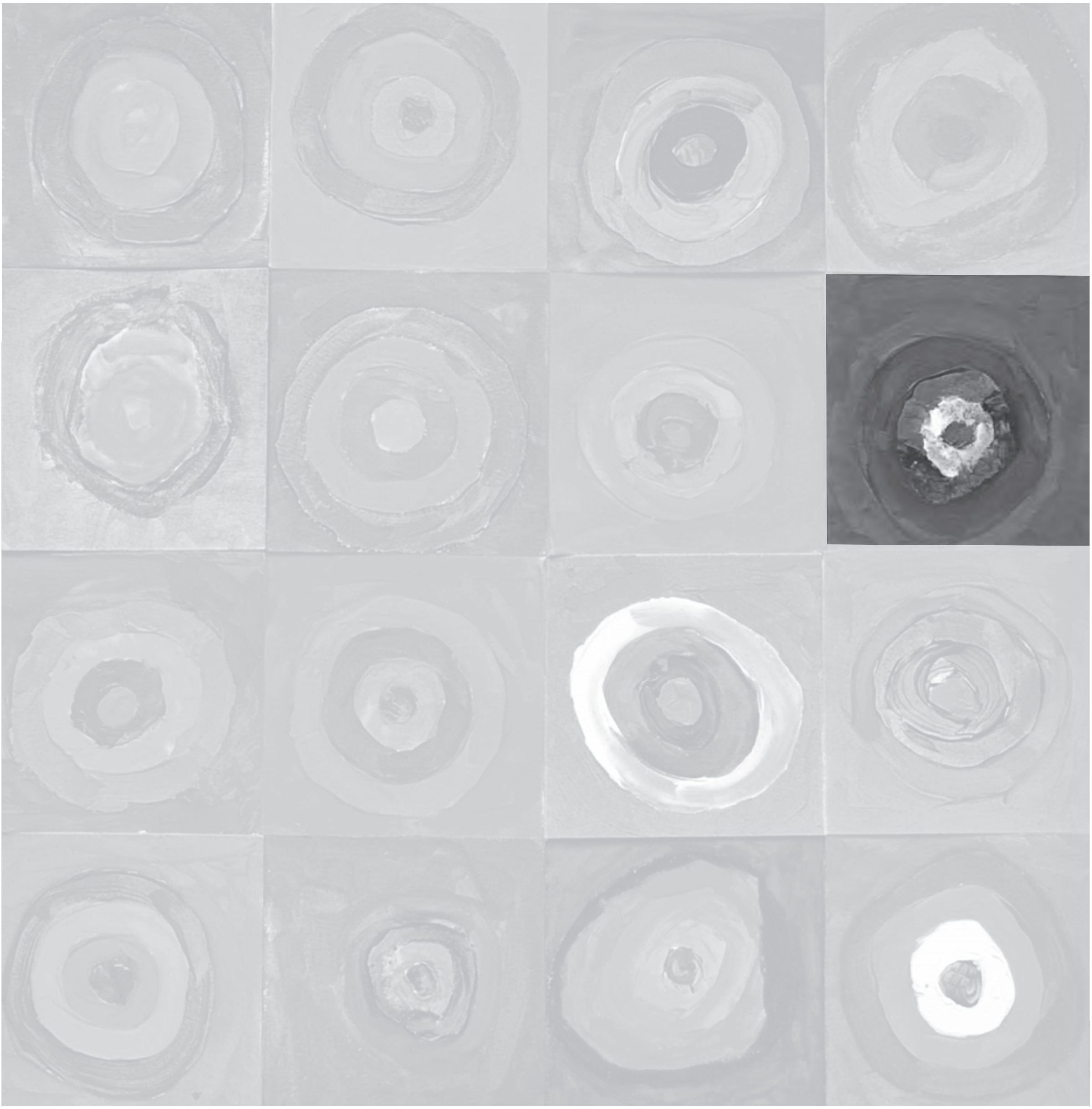


Summary

Summary

The studies presented in this thesis focus on the social networks of people with mild intellectual disabilities (ID). Social networks include family, friends, neighbours, colleagues and acquaintances, also called the informal network. Social networks can also include professionals, called the formal network. A social network is crucial for social inclusion and the quality of life (QOL) of people with mild ID. If social networks are small or social support is perceived as insufficient, professionals have an important role in strengthening and expanding these social networks. Therefore this thesis focuses not only on the characteristics of the social networks, but also on interventions to strengthen and expand those networks.

In the general introduction (**chapter 1**) a brief overview of background information is given about social inclusion, policy, people with mild ID, their social networks and network interventions. Social inclusion encompasses two domains, social relationships and community participation. In this thesis we focused on the first domain, the network of social relationships. Analysis of social networks of people with mild ID includes not only the size and composition of the network, but also other structural characteristics, such as accessibility, length of the relationship and initiation and frequency of the contact. In addition, network analysis focuses on so-called functional characteristics such as emotional and practical support. An increasing number of people with ID live in the community, with the goal of increasing their social participation. The Social Support Act (Wet maatschappelijke ondersteuning, Wmo) expects independence from public services, self-reliance and 'personal strengths' and, if necessary, support from a person's own informal networks. However, people with mild ID (IQ 50-69) and people with borderline ID (IQ 70-85) increasingly apply for professional support, partly related to a lack of adequate support from their informal networks. Therefore, this thesis focuses on the networks of people with mild to borderline ID. For the sake of readability we use 'mild ID', by which we generally mean 'mild to borderline ID'. Based on an outline of research on social networks and network interventions, chapter 1 concludes that (a) a comprehensive picture of the characteristics of the social networks of people with mild ID from their own perspective has been lacking; and (b) that little is known about the experiences of people with mild ID and their support workers with network interventions and the effect of these interventions. Chapter 1 ends with the aims and the research questions of the thesis. The first aim was to provide a comprehensive picture of the specific network characteristics from the perspectives of people with mild ID themselves. The second aim was to gain insight into network interventions and how well they succeed. With these aims in mind, we posed the following research questions. What are the specific network characteristics and specific network perceptions of people with mild ID? What are the experiences of professionals with regard to strengthening and expanding the social networks of clients with mild ID? What are the results of a social network intervention aimed at enhancing the social networks of people with mild ID?

The thesis consists of two parts. The first part contains three chapters (chapters 2, 3 and 4) and focuses on the network characteristics from the perspective of people with mild ID. In this first part of the thesis a mainly quantitative approach was used. The second part (chapters 5 and 6) focuses on network interventions. In this part a mainly qualitative approach was used.

In the **first part** we used the Maastricht Social Network Analysis (MSNA) adapted for people with mild ID to map the structural characteristics (e.g. accessibility, length of the relationship, initiation and frequency of contact) and functional characteristics (i.e. affection, connection, preference and practical/informational support) of the social networks of the participants.

Chapter 2 examines the social networks of 33 participants with mild ID who all lived independently in the community. Their social networks varied from four to 28 members (*Mean* 14.2): family members (42.7%), acquaintances, such as friends, neighbours colleagues and other acquaintances (32.8%) and professionals (24.5%). It was remarkable that (a) they had a high frequency of contact with network members; (b) the participants often considered themselves to be the main initiator of contact; (c) professionals were often assigned high scores for functional characteristics; and (d) network members were assigned relatively low scores for the connection characteristic of the social networks.

In addition we examined, in **chapter 3,** the extent to which people with mild ID are satisfied with their networks and what wishes they have regarding their networks. We also examined which network characteristics relate to satisfaction with the network and perceived QOL. We used a questionnaire about satisfaction and wishes and the Intellectual Disability Quality of Life (IDQOL). The majority of the participants (73.1%) were satisfied with their social networks. Improvement in the area of strengthening existing ties (e.g. more frequent contact, better contact) was desired as opposed to expansion of the network. Affection – especially towards family and professionals – was most strongly positively related to perceived QOL. With respect to size of network, the number of acquaintances was seen as important. For the other characteristics of the network, family seemed crucial. It appeared to be essential that relatives lived in the same town, were able to meet up frequently and provided both emotional and practical support.

However, both in chapters 2 and 3 we did not compare our findings with a reference group. Therefore, in **chapter 4** we compared the social networks of people with mild ID with a reference group and with people with Autism Spectrum Disorders (ASD). The reference group was a group of people with a comparable age and gender, without ID or ASD. The aim of this study was to determine the similarities and differences in social network characteristics, satisfaction and wishes. As well as the 33 people with mild ID, 42 people from the reference group and 30 people with ASD also participated. Compared to the reference group, people with mild ID and people with ASD had less network members on their ecograms, showing that their networks were more restricted. They also considered that the initiation of the contact was less often reciprocal and they were less often satisfied with their network. In comparison with both other groups, people with mild ID (a) considered themselves to be the main initiator of contact more often; (b) have known their acquaintances for a shorter duration, saw them more often and wished to improve these contacts; and (c) wished to have more frequent contact with family members.

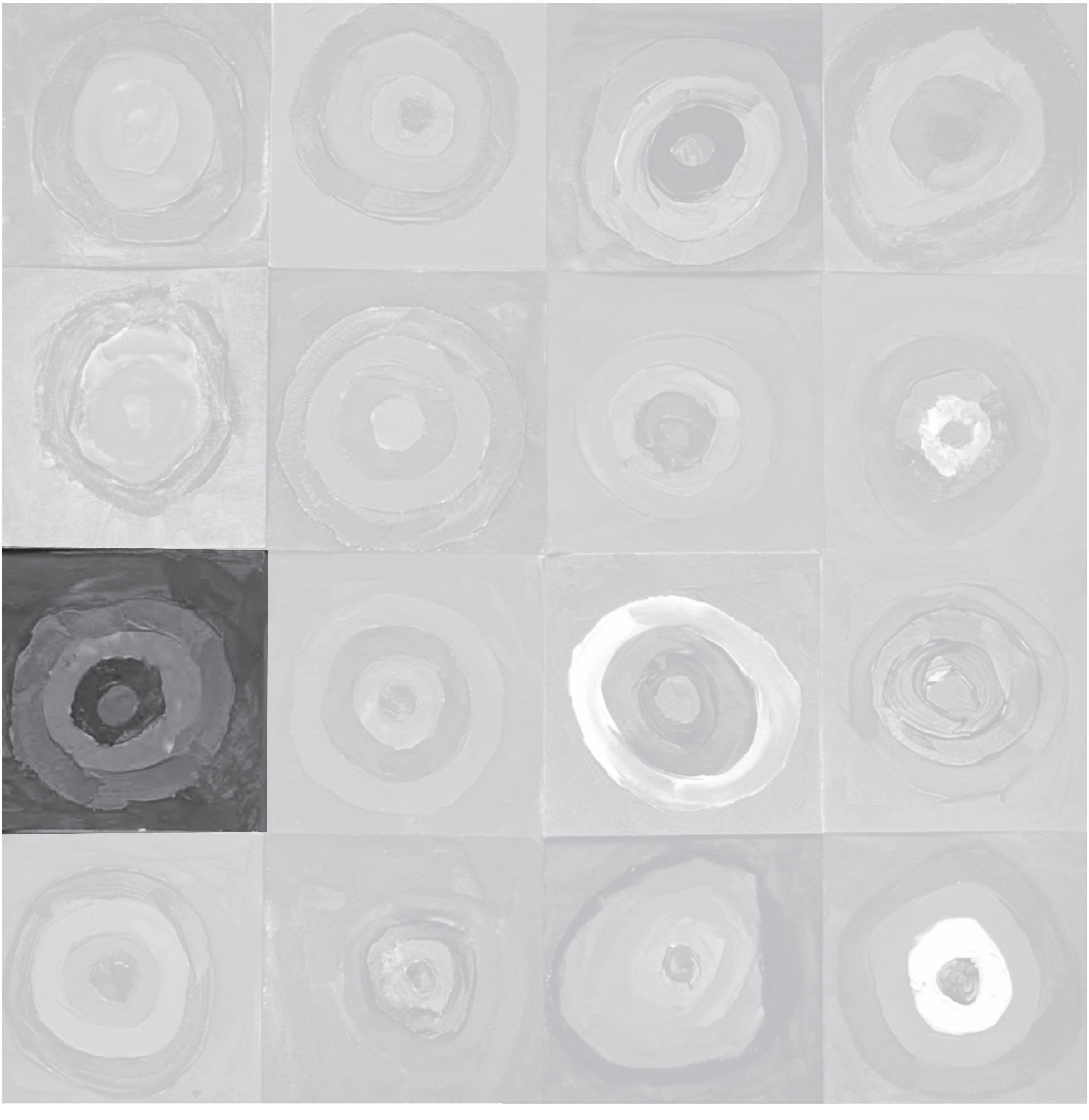
In the **second part** we focused on network interventions. Two studies were performed, firstly on the experiences of professionals with network interventions (chapter 5) and secondly an intervention study (chapter 6).

Because the role of professionals in the networks was found to be important in the first part of the thesis, we focused in **chapter 5** on the perspective of professionals and their experiences with network interventions aimed at strengthening and expanding the social networks of people with mild ID. The results showed interventions to strengthen social networks (e.g. attention to the maintenance of contact with network members) and interventions to expand social networks (e.g. participation in leisure time activities and working with volunteers). However, a large number of impeding factors were mentioned by support staff, such as the limited size of the social networks, characteristics of the client, different perceptions and clients falling between the cracks when it comes to leisure time. Facilitating factors were also mentioned, such as making use of a plan, matching of interests, awareness and a customized, individualized approach. However, the large number of impeding factors showed that the strengthening and expansion of social networks is complicated in actual practice.

Finally, we conducted an intervention study, described in **chapter 6**, based on the findings of chapter 5. An intervention fitting with the aforementioned facilitating factors was *'Die Ken Ik!'* [*I know them!*], a group training for people with mild ID, offered by a self-advocacy group. Moreover, the themes of this intervention were based on *Person Centered Planning (PCP)*, an internationally well-known intervention, with positive outcomes on social participation. Based on the finding that, in actual practise, it is hard to alter social networks (chapter 5), we combined the group training for participants with mild ID with training for their support staff and added coaching sessions to the intervention. We conducted a multiple case analysis to examine the results of this intervention in the lives of people with ID. Although participants and their networks appear to be vulnerable, the findings were promising and in line with former PCP research. For instance, the participants felt more aware of themselves and their network, they learned to make contact and to ask for help and felt more autonomous. Moreover, they experienced an enhancement of their networks, a decrease in loneliness and an increase in community participation. The overall findings show an indicative level of evidence for the effectiveness of the intervention.

In **chapter 7**, the main findings of the thesis are summarized, and the strengths and limitations are discussed, related to choices of sample size, inclusion criteria, participants, measures, and the level of interventions. Given

the relatively small sample size and the inclusion criteria, generalization of our findings to people with mild ID is restricted, in particular to those with additional behaviour problems. However, the MSNA gave a large amount of information on the social networks of people with mild ID from their own perspective. In addition, the combination of quantitative and qualitative measures and the different points of view (i.e. mainly those of people with ID themselves, but also those of their support workers and trainers) provide an in-depth understanding of the complexity of network interventions in a social context. Several recommendations are made for future research, such as to repeat the intervention study with more participants, to examine network interventions for people with mild ID and additional behaviour problems and to investigate interventions at the organizational and community level. Finally recommendations are made for policy, practice and the education of future support workers. It is important to map social networks systematically, to pay attention to the qualitative aspects of the network and to the opinions of the person himself. Questions regarding satisfaction are of interest, but our findings show that people who said that they were satisfied with their network were sometimes very lonely and had multiple wishes for their network. Thus, it is important to continue to ask questions regarding loneliness or wishes and to give some concrete options, to get better insight into the needs of the person. The thesis emphasizes the important role of support workers in the lives of people with mild ID. Both policy makers and support workers can take this into account, when support may be reduced or a support worker may be replaced. A good way to involve informal network members more is to organize supporters' meetings, in which network members think along with the person with respect to their wishes and dreams. Also, in regular conversations network members can be invited to think along. The results indicate that it is important to pay attention to the interests of the person and to expend effort to bring people with similar interests together. In the discussion we emphasize that informal network members and formal network members are not interchangeable. In their new role, support workers include the perspectives of their clients and their network members, involve these network members, meet needs to strengthen and expand networks and tune the level of support to the changing needs of their clients and their networks.



Samenvatting

Samenvatting

Het onderzoek dat beschreven is in dit proefschrift richt zich op de sociale netwerken van mensen met lichte verstandelijke beperkingen (LVB). Bij sociale netwerken gaat het om familie, vrienden, buren, collega's en kennissen; dit wordt ook wel het informele netwerk genoemd. Daarnaast kan het bij het sociale netwerk ook om professionals gaan; dit wordt ook wel het formele netwerk genoemd. Een sociaal netwerk is cruciaal voor de sociale inclusie en de kwaliteit van bestaan van mensen met LVB. Als netwerken klein zijn of onvoldoende steun bieden, hebben professionals een belangrijke taak in het versterken en uitbreiden ervan. Daarom richt dit proefschrift zich niet alleen op de kenmerken van de sociale netwerken, maar ook op interventies om deze netwerken te versterken of uit te breiden.

In de algemene introductie (**hoofdstuk 1**) wordt een kort overzicht gegeven van achtergrond-informatie over sociale inclusie, beleid, mensen met LVB, hun netwerken en netwerkinterventies. Sociale inclusie richt zich op twee domeinen: sociale relaties en participatie in de samenleving. In dit proefschrift hebben we ons gericht op het eerste domein: het netwerk van sociale relaties. Bij de analyse van het sociale netwerk van mensen met LVB gaat het niet alleen om omvang en samenstelling, maar ook om andere structurele kenmerken zoals bijvoorbeeld bereikbaarheid, duur van de relatie, initiatief en frequentie van het contact. Daarnaast richt een netwerkanalyse zich op zogenaamde functionele aspecten, zoals emotionele en praktische steun. Steeds meer mensen met een verstandelijke beperking wonen zelfstandig in de samenleving met als doel te participeren in die samenleving. De Wet maatschappelijke ondersteuning (Wmo) verwacht onafhankelijkheid van maatschappelijke diensten, zelfstandigheid, 'eigen kracht' en indien nodig ondersteuning vanuit het eigen informele netwerk. Mensen met LVB (IQ 50-69) en mensen die zwakbegaafd zijn (IQ 70-85) doen echter in toenemende mate een beroep op professionele ondersteuning, onder andere door een gebrek aan passende ondersteuning vanuit het informele netwerk. Daarom richt dit proefschrift zich zowel op de sociale netwerken van mensen met LVB, als ook op die van mensen die zwakbegaafd zijn. Vanwege de leesbaarheid gebruiken we de term LVB, waar we over het algemeen ook mensen die zwakbegaafd zijn onder verstaan. Gebaseerd op het overzicht van het onderzoek naar sociale netwerken en netwerkinterventies, concluderen we in hoofdstuk 1 dat (a) een uitgebreid en gedetailleerd beeld van de netwerken van mensen met LVB, vanuit hun eigen perspectief, ontbreekt; en (b) dat er weinig bekend is over de ervaringen van mensen met LVB en hun begeleiders met netwerkinterventies en over het effect van deze interventies. Hoofdstuk 1 eindigt met de doelen en onderzoeksvragen van het proefschrift. Het eerste doel was om een uitgebreid beeld te schetsen van de structurele en functionele netwerkkenmerken vanuit het perspectief van de mensen met LVB zelf. Het tweede doel was het verkrijgen van inzicht in netwerkinterventies en de resultaten van deze interventies. Om deze doelen te bereiken formuleerden we de volgende onderzoeksvragen. Wat zijn de specifieke kenmerken van en opvattingen over het sociale netwerk van mensen met LVB? Wat zijn de ervaringen van professionals met het versterken en uitbreiden van sociale netwerken van mensen met LVB? Wat is het resultaat van een interventie met als doel sociale netwerken van mensen met LVB te verrijken?

Het proefschrift bestaat uit twee delen. Het eerste deel bestaat uit drie hoofdstukken (hoofdstuk 2, 3 en 4) en is gericht op de netwerkkenmerken vanuit het perspectief van mensen met LVB. In dit eerste deel was het onderzoek voornamelijk kwantitatief van aard. Het tweede deel (hoofdstuk 5 en 6) is gericht op netwerkinterventies. Dit onderzoek was voornamelijk kwalitatief van aard.

In het **eerste deel** gebruikten we de Maastrichtse Sociale Netwerk Analyse (MSNA), aangepast voor mensen met LVB, om de structurele kenmerken (bijvoorbeeld bereikbaarheid, duur van de relatie, initiatief en frequentie van het contact) en de functionele kenmerken (bijvoorbeeld affectie, aansluiting, en praktische en informatieve steun) van de sociale netwerken in kaart te brengen.

Hoofdstuk 2 beschrijft het onderzoek naar de sociale netwerken van 33 mensen met LVB, die zelfstandig in de samenleving woonden. Hun sociale netwerken varieerden van vier tot 28 netwerkleden (gemiddeld 14.2). Dit waren familieleden (42.7%), vriendschappelijke contacten, zoals vrienden, kennissen, buren en collega’s (32.8%) en professionals (24.5%). Opvallend was (a) het frequente contact met netwerkleden; (b) de bevinding dat deelnemers zichzelf vaak als initiatiefnemer van het contact zien; (c) de hoge scores die aan professionals werden toegekend voor functionele kenmerken; en (d) de relatief lage scores t.a.v. de aansluiting met netwerkleden.

Vervolgens hebben we in **hoofdstuk 3** onderzocht in welke mate mensen met LVB tevreden zijn met hun netwerk en welke wensen zij hebben ten aanzien van hun netwerk. Ook onderzochten we welke netwerkkenmerken gerelateerd zijn aan tevredenheid met het netwerk en ervaren kwaliteit van bestaan. We gebruikten hierbij een vragenlijst over tevredenheid en wensen en de Intellectual Disability Quality of Life (IDQOL). De meerderheid van de deelnemers (73.1%) was tevreden met het netwerk. Wensen lagen op het vlak van het versterken van bestaande relaties (bijvoorbeeld vaker of beter contact) en niet zozeer ten aanzien van het uitbreiden van het netwerk. Affectie – met name voor wat betreft familie en professionals – was het sterkst positief gerelateerd aan ervaren kwaliteit van bestaan. Met betrekking tot omvang was het aantal vriendschappelijke contacten belangrijk. Voor de andere kenmerken bleek het familienetwerk cruciaal. Het bleek belangrijk dat familieleden in dezelfde plaats wonen, elkaar vaak ontmoeten en emotionele en praktische steun bieden.

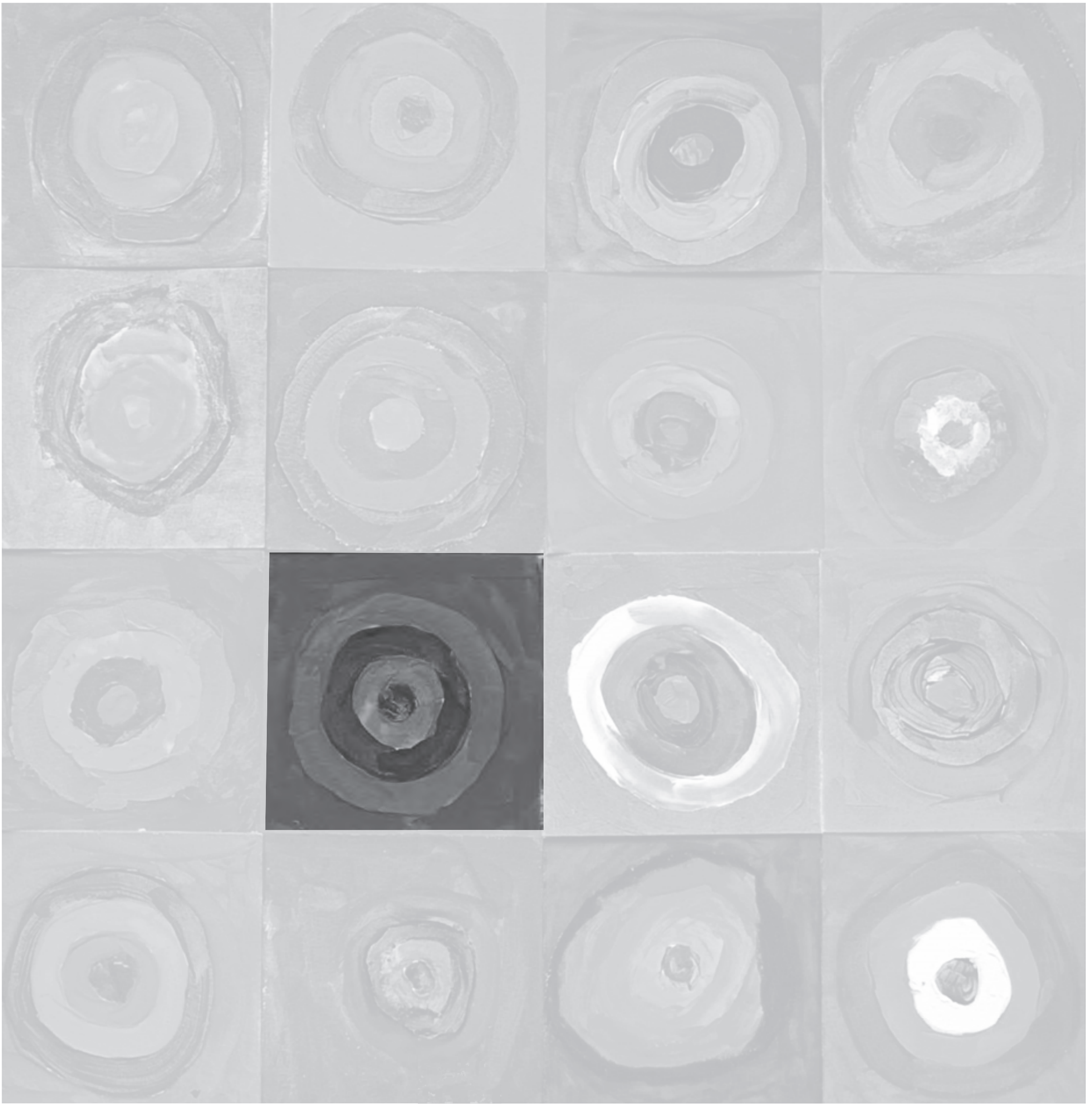
In zowel hoofdstuk 2 als hoofdstuk 3 hebben we echter geen referentiegroep gebruikt om onze resultaten mee te vergelijken. Derhalve hebben we in **hoofdstuk 4** de netwerken van mensen met LVB vergeleken met die van een referentiegroep en van mensen met een Autisme Spectrum Stoornis (ASS). De referentiegroep was qua leeftijd en geslacht vergelijkbaar met de andere groepen en bestond uit mensen zonder LVB of ASS. Doel van dit onderzoek was de overeenkomsten en verschillen in netwerkkenmerken, tevredenheid en wensen te achterhalen. Er namen naast de 33 personen met LVB, ook 42 personen van de referentiegroep en 30 personen met ASS deel. Mensen met LVB en ASS hadden in vergelijking met de referentiegroep minder mensen op hun ecogram, hetgeen laat zien dat hun netwerken beperkter zijn. Ook hadden zij minder vaak het gevoel dat het initiatief in het contact wederzijds was en waren zij minder vaak tevreden met hun netwerk. In vergelijking met beide andere groepen, waren de volgende aspecten kenmerkend voor mensen met een LVB. Mensen met LVB (a) zagen zichzelf vooral als de persoon die het meeste initiatief neemt; (b) kenden hun vriendschappelijke netwerkleden korter, zagen hen vaker en wensten beter contact met hen; en (c) wilden graag vaker contact met hun familieleden.

In het **tweede deel** hebben we ons gericht op netwerkinterventies. We deden twee verschillende studies: een onderzoek naar de ervaringen van professionals met netwerkinterventies (hoofdstuk 5) en een interventiestudie naar een training (hoofdstuk 6).

Omdat in deel 1 van het proefschrift bleek dat de rol van professionals belangrijk is, hebben we ons in **hoofdstuk 5** gericht op het perspectief van professionals en hun ervaringen met interventies gericht op sociale netwerken van mensen met LVB. Uit de resultaten kwamen interventies naar voren om netwerken te versterken (bijvoorbeeld aandacht voor het onderhouden van contacten met netwerkleden) en interventies om netwerken uit te breiden (bijvoorbeeld deelname aan vrijetijdsbesteding en het werken met vrijwilligers). Er werd echter ook een groot aantal belemmerende factoren genoemd, zoals de kleine omvang van de netwerken, kenmerken van de cliënt, verschil in opvatting en het 'tussen de wal en het schip vallen' bij vrijetijdsbesteding. Ook bevorderende factoren werden genoemd, zoals het werken met een plan, aansluiten bij interesses, bewustwording en het bieden van maatwerk. De belemmerende factoren lieten echter zien dat het versterken en uitbreiden van de sociale netwerken in de dagelijkse praktijk lastig is.

Tenslotte hebben we een interventiestudie uitgevoerd, beschreven in **hoofdstuk 6**, gebaseerd op de bevindingen uit hoofdstuk 5. Een interventie die aansloot bij de genoemde bevorderende factoren was *‘Die Ken Ik!’,* een training aangeboden door de belangenvereniging *LFB*. Bovendien zijn de thema’s van deze interventie gebaseerd op *Person Centered Planning*, een internationaal bekende interventie met positieve resultaten voor wat betreft sociale participatie. Omdat uit ons onderzoek bleek dat het in de praktijk moeilijk is om sociale netwerken te veranderen (hoofdstuk 5), hebben we de training voor deelnemers met LVB gecombineerd met een training voor hun begeleiders en hebben we coachingsbijeenkomsten toegevoegd aan de interventie. We hebben een multiple case-analysis uitgevoerd om de resultaten van de interventie te onderzoeken. Hoewel er sprake was van kwetsbaarheid van de deelnemers en hun netwerk, waren de resultaten veelbelovend en in lijn met eerder onderzoek. Zo werden de deelnemers zich bijvoorbeeld meer bewust van zichzelf en hun netwerk, leerden ze contact te maken en om hulp te vragen en voelden zij zich zelfstandiger. Bovendien werden hun netwerken verrijkt, nam hun eenzaamheid af en participeerden zij meer in de samenleving. In zijn algemeenheid lieten de resultaten zien dat de interventie volgens eerste aanwijzingen effectief is.

In **hoofdstuk 7** worden de belangrijkste bevindingen uit het proefschrift samengevat en worden sterke punten en beperkingen bediscussieerd, gerelateerd aan de keuzes met betrekking tot steekproefomvang, inclusiecriteria, deelnemers, instrumenten en het type interventie. Gezien de relatief kleine steekproefomvang en de geformuleerde inclusiecriteria, kunnen de bevindingen beperkt gegeneraliseerd worden naar mensen met LVB in het algemeen en in het bijzonder naar de groep met bijkomende gedragsproblemen. De MSNA leverde echter een grote hoeveelheid informatie op over het netwerk van mensen met een LVB vanuit hun eigen perspectief. Bovendien gaf de combinatie van kwantitatieve en kwalitatieve instrumenten en het betrekken van verschillende perspectieven (namelijk vooral die van de mensen met LVB zelf, maar ook die van begeleiders en trainers) een diepgaand inzicht in de complexiteit van netwerkinterventies in de praktijk. Diverse aanbevelingen worden gedaan voor toekomstig onderzoek, zoals het herhalen van het interventie-onderzoek met meer deelnemers, het onderzoeken van netwerkinterventies bij mensen met LVB en bijkomende gedragsproblemen en het onderzoeken van interventies op het niveau van de organisatie en de samenleving. Tenslotte worden er aanbevelingen gedaan voor beleid, praktijk en opleiding van toekomstige begeleiders. Het wordt van belang geacht sociale netwerken systematisch in kaart te brengen en daarbij oog te hebben voor de kwalitatieve aspecten ervan en voor de mening van de persoon zelf. De vraag naar tevredenheid met het netwerk is van belang, maar ons onderzoek liet zien dat ook mensen die aangaven tevreden te zijn, soms erg eenzaam waren en veel netwerkwensen hadden. Het is dus van belang door te vragen naar eenzaamheid en wensen en hierbij concrete opties te noemen om beter zicht te krijgen op de behoeften van de persoon. Het proefschrift benadrukt ook de belangrijke rol die begeleiders spelen in het leven van mensen met LVB. Zowel beleidsmakers als begeleiders kunnen daar rekening mee houden wanneer er sprake is van vermindering van begeleidingsuren of vervanging. Een manier om informele netwerkleden meer te betrekken is het organiseren van supportersbijeenkomsten, waarbij netwerkleden meedenken met de persoon over het realiseren van wensen of dromen. Ook in reguliere gesprekken kunnen netwerkleden uitgenodigd worden om mee te denken. De resultaten uit het onderzoek impliceren dat het belangrijk is uit te gaan van de interesses van de persoon en mensen met dezelfde interesses met elkaar in contact te brengen. In de discussie wordt benadrukt dat informele netwerkleden en formele netwerkleden niet inwisselbaar zijn. In hun nieuwe rol betrekken begeleiders de perspectieven van cliënten én hun netwerkleden, betrekken zij deze netwerkleden, hebben zij oog voor de behoefte aan een sterker of groter netwerk en stemmen zij de mate van ondersteuning af op de wisselende behoeften van hun cliënten en hun netwerk.



Easy read summary

Easy read summary

What is this book about?

This book is about social networks.
What is a social network?
A social network is all the people that you know and who are important to you.
For instance family, friends, neighbours, colleagues, acquaintances and support workers.

A social network is important for everybody.
If you experience something good or bad, you can talk about it and get support from network members.
Others can help you if you don't know something or if you aren't able to do something.
It is nice to belong to a group.
It is nice to do things together with other people.

This book is about the social networks of people with mild intellectual disabilities.
Their networks are not always large.
Sometimes people don't get enough support from their network members.
Support workers can support people to make their network bigger or stronger.
A bigger network means that you meet more people.
A stronger network means that you have better of more frequent contact with the people you already know.

Our research aimed to answer 3 questions:

1. What do the networks of people with a mild intellectual disability look like?
2. How you can make networks bigger and stronger?
3. What are the results of a course aimed at making networks bigger and stronger?

Question 1. What do the networks of people with a mild intellectual disability look like?

Who?

We asked 33 adults with mild intellectual disabilities about their social network.
They all lived on their own, not in a group home and not with their parents.
They all got support.
We also asked people without intellectual disabilities about their social network so that we could compare the networks.

How?

We visited the people.
We asked: 'Who do you know and who is important to you?'
And then we asked questions about each person.
We wrote down the answers to the questions.

Here are some of these questions:
How often do you have contact with this person?
How long have you known this person?
Who takes initiative for meeting up?
That means: who takes care of making the appointment.

How safe do you feel with this person?
Do you like the same things? Are the same things important to you?
Does the person help you, if you don't know something or aren't able to do something?

How satisfied are you with your network and your life?
What wishes do you have?

What?

What were the results of this research project?
People have, on average, 14 people in their networks.
About a quarter are support workers.
People without a disability have a larger network.

People with mild intellectual disabilities know their friends and acquaintances for a shorter duration.
They see them more often.
They feel that they take initiative in making contact more often.

Support staff are important for them.
They feel safe and secure with them.
Support workers give support when they don't know something or aren't able to do something.

Family members are very important for people with mild intellectual disabilities.
They like family to give support.
They like family to live in the same town.
They like to meet each other often.

Many people with mild intellectual disabilities are satisfied with their network.
People without disabilities are even more often satisfied with their network.

Question 2. How you can make networks bigger and stronger?

Who?

We did interviews with groups of support workers.
27 persons participated.

How?

We asked questions of groups of support workers.
How do you make networks bigger or stronger?
How does this happen in your organization?

What?

Support staff know ways to strengthen or expand networks.
For instance, you can get to know people when you go to a sports club or other club.
Or look for a volunteer or buddy.
Support workers can give support to maintain contacts.
For instance help to send a card.
Or help when there is a quarrel with someone.

Support workers think it is very difficult to expand and strengthen networks.
They mentioned 24 different things that were difficult.
Some people have a very small network.
For some people it is very difficult to make contacts and to maintain them.
Others don’t feel at home at, for instance, a special sports club for people with intellectual disabilities.

Some people also don't feel at home at a sport club for everybody.
So, it is quite difficult to change networks.

They also mentioned things that worked well.
Looking at the interests of a person.
What does the person like to do?
And asking: who has the same interests?

Question 3. What are the results of a course aimed at making networks bigger and stronger?

Who?

This project was about 5 persons with mild intellectual disabilities and their support workers.
They went on a course together.

How?

The course is called *'I know them!'*
The course is given by the LFB.
The LFB is a self-advocacy group run by and for people with disabilities.
The LFB employs people who have mild intellectual disabilities themselves.
'I know them!' is a course to make networks bigger or stronger.
We changed a few things in the course.
Support workers went along on the course.
And, after the course, support staff and participants were supported for some time.
Because a network change takes time and can be difficult.

We asked the participants with disabilities, their support workers and trainers questions.
We did that before the course, after the course and at the very end.
We visited the participants at home.
We talked and wrote down the answers to the questions.

For example, on what does their network look like.
Whether anything changed in the network.
Whether people felt lonely.
Whether people felt that they themselves could choose things.
How they saw themselves.
And what they thought of the course and what they had learned from it.

What?

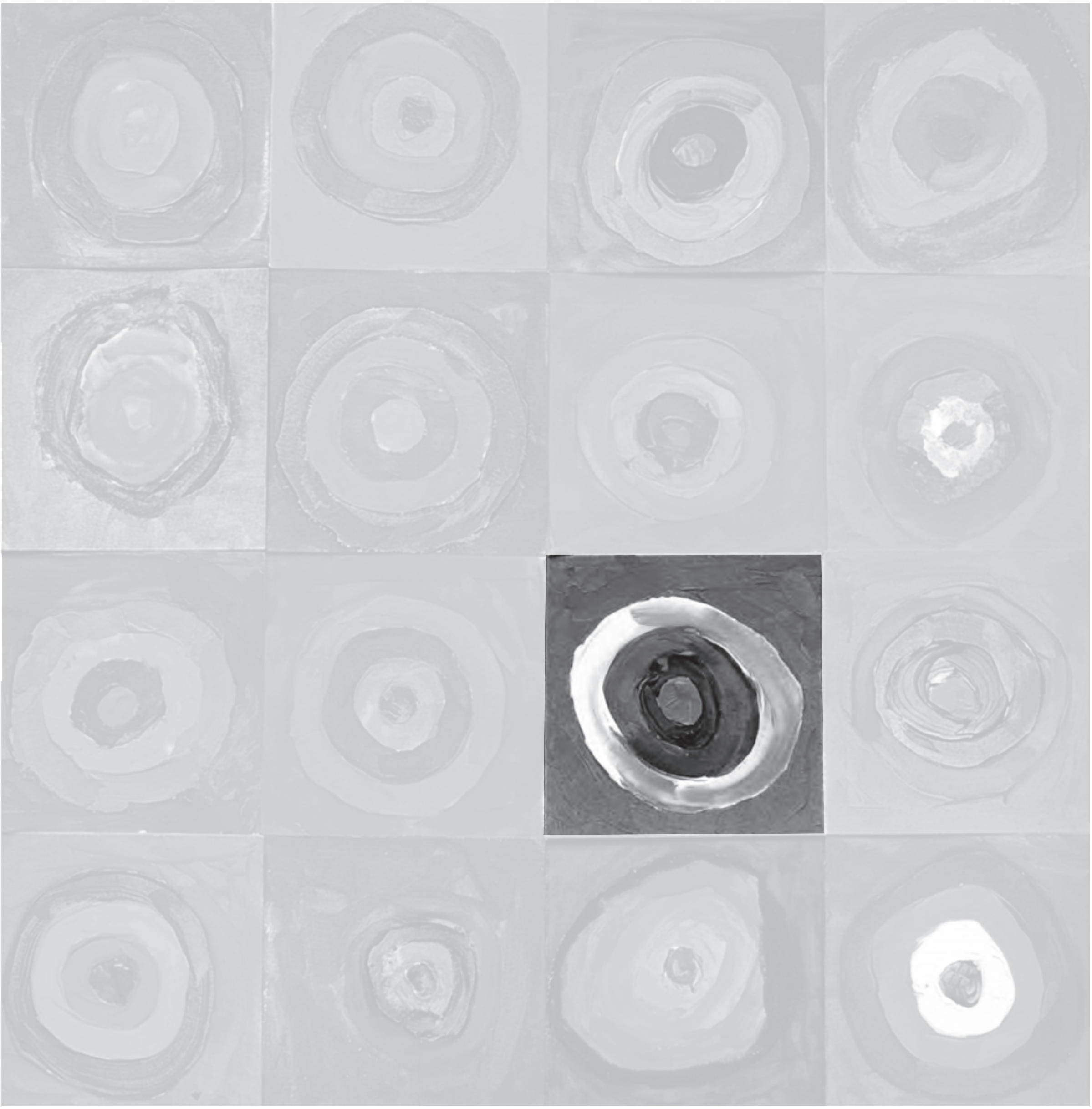
The participants in the course have learned a lot.
They are more aware of themselves and their network.
They chat more easily.
They dare to ask for help more often.
They make more choices themselves.

For everyone there were some positive changes in their network.
Some now know more people.
Others have better contact with the people they already knew.
They are therefore less lonely.
They also go out more often.

Sometimes, participants had their ups and downs.
They sometimes worried.
About their own health and that of the people around them.
Sometimes there were intense quarrels in their families.
Network changes don't come easily.
It is important that support workers help with the network changes.

Conclusion

We now know better what the networks of people with a mild intellectual disabilities look like.
It is difficult to change these networks.
The course *'I Know them!'* can help with that.
It is important that support workers participate.
Then they can support people at times when it is difficult.



Samenvatting in gewone taal

Samenvatting in gewone taal

Waarover gaat dit boek?

Dit boek gaat over sociale netwerken.
Wat is een sociaal netwerk?
Het zijn alle mensen die je kent en die belangrijk voor je zijn.
Bijvoorbeeld familie, vrienden, buren, collega's, kennissen en begeleiders.

Een sociaal netwerk is voor iedereen erg belangrijk.
Als je iets leuks of naars meemaakt kun je er over praten en steun krijgen.
Anderen kunnen je helpen als je iets niet weet of kunt.
Het is fijn om bij een groep te horen.
Het is gezellig om samen met andere mensen dingen te doen.

Het boek gaat over sociale netwerken van mensen met een lichte verstandelijke beperking.
Hun netwerken zijn niet altijd groot.
Mensen krijgen soms niet voldoende steun van hun sociale netwerk.
Begeleiders kunnen ondersteunen om het netwerk groter of sterker te maken.
Groter maken betekent: nieuwe mensen leren kennen.
Sterker maken is: beter contact of vaker afspreken met de mensen die je al kent.

We deden onderzoek om 3 vragen te beantwoorden:

1. Hoe zien netwerken van mensen met een lichte verstandelijke beperking eruit?
2. Hoe maak je netwerken sterker en groter?
3. Wat zijn de resultaten van een cursus gericht op het sterker of groter maken van het netwerk?

Vraag 1. Hoe zien netwerken van mensen met een verstandelijke beperking eruit?

Wie?

We stelden vragen aan 33 volwassenen met een lichte verstandelijke beperking.
De mensen woonden allemaal zelfstandig.
Dus niet in een groep en niet bij hun ouders.
Ze kregen allemaal begeleiding.
We stelden ook vragen aan mensen zonder verstandelijke beperking.
Om de netwerken te kunnen vergelijken.

Hoe?

We gingen bij mensen op bezoek.
We vroegen: 'Wie ken je en zijn belangrijk voor je?'
En dan stelden we over elke persoon vragen.
We schreven de antwoorden op de vragen op.

Hieronder staan een aantal van die vragen.
Hoe vaak heb je contact met deze persoon?
Hoe lang ken je die persoon al?
Wie neemt initiatief als je afspreekt?
Dat betekent: wie zorgt ervoor dat jullie afspreken?

Hoe veilig en vertrouwd voel je je bij die persoon?
Vind je dezelfde dingen leuk of belangrijk?
Als je iets niet weet of kan, helpt die persoon je dan?
Hoe tevreden ben je met je netwerk en je leven?
Welke wensen heb je?

Wat?

Wat kwam er uit het onderzoek?
De mensen hebben gemiddeld 14 mensen in hun netwerk.
Ongeveer een kwart zijn begeleiders.
Mensen zonder verstandelijke beperking hebben een groter netwerk.

Mensen met een lichte verstandelijke beperking kennen hun vrienden en kennissen korter.
Ze zien hen vaker.
Ze hebben vaker het gevoel dat zij zelf initiatief nemen in het contact.

Begeleiders zijn belangrijk voor hen.
Zij voelen zich veilig en vertrouwd bij hen.
Begeleiders geven steun als ze iets niet weten of kunnen.

Familieleden zijn heel belangrijk voor mensen met een lichte verstandelijke beperking.
Ze vinden het fijn als familie steun biedt.
Ze vinden het fijn als familie in dezelfde plaats woont.
Ze vinden het fijn elkaar vaak te zien.

Veel mensen met een lichte verstandelijke beperking zijn tevreden met hun netwerk.
Mensen zonder verstandelijke beperking zijn nog vaker tevreden met hun netwerk.

Vraag 2. Hoe maak je netwerken sterker en groter?

Wie?

We hebben interviews gehouden met groepen begeleiders.
27 mensen deden mee.

Hoe?

We stelden vragen aan groepen begeleiders.
Hoe kun je een netwerk sterker of groter maken?
Hoe gaat dat bij jullie?

Wat?

Begeleiders kennen manieren om een netwerk sterker of groter te maken.
Je kunt bijvoorbeeld mensen leren kennen als je naar een sport of club gaat.
Of een vrijwilliger of maatje zoeken.
Begeleiders kunnen steun geven bij het contact houden.
Bijvoorbeeld helpen een kaartje te sturen.
Of helpen als er een ruzie is met iemand.

Begeleiders vinden het erg lastig om netwerken groter en sterker te maken.
Ze noemden 24 verschillende dingen die lastig zijn.
Sommige mensen hebben een heel klein sociaal netwerk.
Voor sommigen is het heel moeilijk om goed contact te leggen en te houden.

Anderen voelen zich niet echt thuis bij bijvoorbeeld een
sportclub speciaal voor mensen met een verstandelijke
beperking.
Maar ook niet bij een sportclub die voor iedereen is.
Het is dus best moeilijk om een sociaal netwerk te veranderen.

Er werden ook dingen genoemd die goed werken.
Kijk naar de interesses van iemand.
Wat vindt iemand leuk om te doen?
En kijk wie dezelfde interesses heeft.

Vraag 3. Wat zijn de resultaten van een cursus gericht op het sterker of groter maken van het netwerk?

Wie?

Dit onderzoek ging over 5 mensen met een lichte verstandelijke beperking.
En hun begeleiders.
Zij volgden samen een cursus.

Hoe?

De cursus heet *'Die Ken Ik!'.*
Het is een cursus van de LFB.
De LFB is een belangenvereniging voor en door mensen met een beperking.
Er werken mensen die zelf ook een lichte verstandelijke beperking hebben.
'Die Ken Ik!' is een cursus om het netwerk sterker of groter te maken.
We hebben een paar dingen aangepast aan de cursus.
Begeleiders gingen mee op cursus.
En na de cursus werden de begeleiders en deelnemers nog een tijd ondersteund.
Want een netwerk veranderen kost tijd en kan moeilijk zijn.

We hebben vragen gesteld.
Aan de deelnemers met een beperking, hun begeleiders en trainers.
Dat deden we voor de cursus, na de cursus en helemaal aan het eind.
We gingen bij de mensen op bezoek.
We hadden een gesprek en vulden vragenlijsten in.
Bijvoorbeeld over hoe het netwerk eruit ziet.
Of daarin iets veranderde.
Of mensen zich eenzaam voelden.
Of mensen het gevoel hadden dat ze zelf dingen mogen kiezen.
Hoe ze naar zichzelf keken.
En wat ze van de cursus vonden en wat ze ervan geleerd hadden.

Wat?

De deelnemers aan de cursus hebben veel geleerd.
Ze zijn zich meer bewust van zichzelf en hun sociale netwerk.
Ze maken makkelijker een praatje.
Ze durven meer om hulp te vragen.
Ze kiezen meer zelf.

Bij iedereen is er wel iets positiefs veranderd in het sociale netwerk.
Sommigen kennen nu meer mensen.
Anderen hebben beter contact met de mensen die ze al kenden.
Ze zijn daardoor minder eenzaam.
Ze gaan ook vaker erop uit.

Het gaat soms op en neer met de deelnemers.
Ze maken zich soms zorgen.
Om hun eigen gezondheid en die van de mensen om hun heen.
Soms zijn er heftige familieruzies.
Veranderingen in een netwerk gaan niet vanzelf.
Het is belangrijk dat begeleiders daarbij ondersteunen.

Conclusie

We weten nu beter hoe de sociale netwerken van mensen met een lichte verstandelijke beperking eruit zien.
Het is moeilijk deze netwerken te veranderen.
De cursus *'Die Ken Ik!'* kan daarbij helpen.
Het is belangrijk dat begeleiders meedoen.
Dan kunnen zij de deelnemers ondersteunen op momenten dat het moeilijk is.

Dankwoord
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Curriculum Vitae

Ida van Asselt-Goverts (1972) attended high school at *Chr. Lyceum Dr. W.A. Visser 't Hooft* in Leiden (1984-1990). From 1990 to 1994 she studied *Social Work and Services* at *Chr. Hogeschool De Vijverberg* in Ede. After graduation, she worked as an assistant recreational therapist at the *Princess Basma Centre for Children with Disabilities,* in Jerusalem, Israel (1995-1996) and as a support worker in two group homes for adults with intellectual disabilities in Ede: *Slunterhof* and *Bergveste* (1994-2000). From 1996 to 2000 she studied at *Utrecht University* in the *Faculty of Social and Behavioural Sciences, Department of Pedagogical and Educational Sciences*. She specialized in intellectual disabilities. In her master thesis she did a systematic literature review on the quality of care of people with intellectual disabilities and research into the psychometric quality of a scale measuring the perceived competence and social acceptance of people with intellectual disabilities. She worked as social worker at the *SPD/MEE* in Utrecht, providing advice and support to people with intellectual disabilities and their families (2000-2004). Since 2004 she has worked as a teacher, coach and assessor of students at the *HAN University of Applied Sciences* at the *Faculty of Health and Social Studies*, for *Educational Theory*. Alongside this, she has worked as a researcher in the HAN research group *Care for People with Intellectual Disabilities***.** In this group, she started in 2010 her PhD research at *Tilburg University*, under the supervision of prof. dr. P. J. C. M. Embregts and dr. A. H. C. Hendriks. The results of this research, focused on the social networks of people with mild intellectual disabilities, are described in this thesis.

Curriculum Vitae

Ida van Asselt-Goverts (1972) ging in Leiden naar de middelbare school: *Chr. Lyceum Dr. W.A. Visser 't Hooft* (1984-1990). Van 1990 tot 1994 studeerde zij *Maatschappelijk Werk en Dienstverlening* aan de *Chr. Hogeschool De Vijverberg* in Ede. Na haar afstuderen werkte ze als assistent binnen de recreatietherapie van het *Princess Basma Centre for Children with Disabilities,* in Jeruzalem, Israël (1995-1996) en als begeleider in woonvoorzieningen voor volwassenen met een verstandelijke beperking in Ede: *Slunterhof* en *Bergveste* (1994-2000). Van 1996-2000 studeerde zij *Pedagogische Wetenschappen* aan de *Faculteit Sociale Wetenschappen* van de *Universteit Utrecht*. Ze specialiseerde zich in verstandelijke beperkingen. In haar afstudeeronderzoek deed zij een systematisch literatuuronderzoek naar de kwaliteit van zorg voor mensen met een verstandelijke beperking en onderzoek naar de psychometrische aspecten van een schaal die zelfwaargenomen competentie en sociale acceptatie meet bij mensen met een verstandelijke beperking. Ze werkte als zorgconsulent bij de *SPD/MEE* in Utrecht en gaf daar advies en ondersteuning aan mensen met een verstandelijke beperking en hun families (2000-2004). Sinds 2004 werkt zij als docent, begeleider en beoordelaar van studenten bij de *Hogeschool van Arnhem en Nijmegen,* bij de *Faculteit Gedrag, Gezondheid en Maatschappij*, opleiding *Pedagogiek*. Daarnaast werkt zij als onderzoeker bij het HAN *Lectoraat Zorg voor Mensen met een Verstandelijke Beperking.* Binnen dit lectoraat begon zij in 2010 met haar promotieonderzoek bij de *Universiteit van Tilburg,* onder begeleiding van prof. dr. P. J. C. M. Embregts and dr. A. H. C. Hendriks. De resultaten van dit onderzoek, gericht op de sociale netwerken van mensen met een lichte verstandelijke beperking, zijn beschreven in dit proefschrift.

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