

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

A. E. van Asselt-Goverts,^{1,2} P. J. C. M. Embregts^{1,2,3,4} & A. H. C. Hendriks^{1,3,5}

¹ Faculty of Health and Social Studies, HAN University of Applied Sciences, Nijmegen, The Netherlands

² Tranzo, Tilburg University, Tilburg, The Netherlands

³ Dichterbij Innovation and Science, Genep, The Netherlands

⁴ Medical & Clinical Psychology, Tilburg University, Tilburg, The Netherlands

⁵ School of Educational Science, Faculty of Social Sciences, Radboud University, Nijmegen, The Netherlands

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.

Keywords intellectual disabilities, quality of life, satisfaction, social network characteristics, wishes

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

Correspondence: Mrs Ida van Asselt-Goverts, Faculty of Health and Social Studies, HAN University of Applied Sciences, P.O. Box 6960, 6503 GL, Nijmegen, The Netherlands (e-mail: Ida.vanAsselt@han.nl).

(Verdugo *et al.* 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 *et al.* 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 standardised 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 *et al.* 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 *et al.* 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 *et al.* 1997; Gregory *et al.* 2001; Stenfert Kroese *et al.* 2002; Duvdevany & Arar 2004). Moreover better SWB or QOL was found to be associated with more frequent contact with friends (Emerson & Hatton 2008; Cram & Nieboer 2012), but not with family (Emerson & Hatton 2008). Also an association of life satisfaction/subjective QOL with perceived social support has been found (Lunsky & Benson 2001; Bramston *et al.* 2005; 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. Emerson & Hatton 2008; Cram & Nieboer 2012).

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?

Method

Participants

Clients from seven care organisations, located in the south-east of the Netherlands, participated in this research. All organisations 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

organisation varied from 2 to 7. All participants received support from staff from the care organisation; 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 4 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 2 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).

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 operationalised 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 visualisation. 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 visualise 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 visualised 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

visualised 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 *et al.* 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 0.85 for adults with ID (Hoekman *et al.* 2001) to 0.83/0.84 for proxies of children with ID (Cram & Nieboer 2012) and 0.74 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 0.74.

Procedure

The scientific and ethics committee from *Dichterbij*, one of the seven organisations participating in this research, approved the present study. The support staff from the organisations 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.

Data analysis

The data were processed and analysed using SPSS. To map the social networks of the participants, both the total network and different groups within the network were analysed: 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 subcategorised further. Decisions concerning the coding and sub-categorisation 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 analysed 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).

Results

In the following, the satisfaction and wishes of the 33 participants with regard to their social networks will first be summarised. 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.

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

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

Table 1 Satisfaction with the social network (%)

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.

In Table 2, the wishes of the participants with regard to their social networks are summarised. 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 participant 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%).

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, $r = 0.398$, $P = 0.036$.

Table 3 shows the correlations between characteristics of the social network, on the one hand, and satisfaction with the social network and perceived

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

	Satisfaction		QOL	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Structural characteristics				
Size	0.428*	0.023	0.131	0.466
Frequency Face-to-Face	0.100	0.613	0.348*	0.047
Frequency Telephone	0.380*	0.046	-0.083	0.645
Frequency Internet	0.257	0.214	-0.245	0.192
Length [†]	0.138	0.484	-0.049	0.787
Accessibility [‡]	0.410*	0.030	0.217	0.225
Functional characteristics				
Affection	0.152	0.441	0.576***	0.000
Connection	0.065	0.741	0.320	0.070
Preference	0.301	0.120	0.460**	0.007
Practical/Informational support	-0.100	0.611	0.355*	0.043

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

[†] Only for acquaintances and professionals.

[‡] Only for family and acquaintances.

Table 3 Pearson correlations for characteristics of social networks with satisfaction and quality of life (QOL)

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 ($P < 0.05$) 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, $r = 0.448$, $P = 0.017$. And the proportion of family members living in the same place correlated significantly with satisfaction, $r = 0.389$, $P = 0.045$. The other correlations with the size of the network, telephone contact and accessibility of particular groups within the network were not significant for satisfaction.

Analysis of the characteristics of the social networks in relation to the participants' perceived QOL

showed affection to be the most strong predictor ($P < 0.001$). Further exploration revealed that QOL was specifically related with affection assigned to family and professionals, respectively, $r = 0.493$, $P = 0.004$ and $r = 0.624$, $P < 0.001$. 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 ($P < 0.05$). When the participants had a higher preference for contact with family and professionals in the social network, their reported QOL was also higher ($r = 0.390$, $P = 0.027$ and $r = 0.437$, $P = 0.014$ respectively). Practical and informational support from family members was also important for perceived QOL, $r = 0.510$, $P = 0.003$. 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, $r = 0.388$, $P = 0.028$. The more frequent face-to-face contact, the more positive the participants perceived their QOL.

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 $75 \pm 2.7\%$ of the Scale Maximum (SM) for both individuals with as without ID.¹ This can be explained by psychological, homeostatic mechanisms that maintains 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 (Lunsky & Benson 2001; Stenfert Kroese *et al.* 2002; Bramston *et al.* 2005; Miller & Chan 2008). 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 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 *et al.* 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; Verdugo *et al.* 2005; Nota *et al.* 2006; Schmidt *et al.* 2010), the emerging consensus is that people with ID should be asked to give their own views (Verdugo *et al.* 2005; Roeleveld *et al.* 2011). 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

¹ The % SM is defined by Cummins (1995) as: $(\text{score} - 1) \times 100 / (\text{number of scale points} - 1)$.

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 *et al.* 2010; Stalker *et al.* 2011). An approach using multiple sources of information is considered to provide the most accurate and comprehensive picture of social inclusion (Amado *et al.* 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 visualisation. 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 2 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 analyse the extent to which the structural and functional characteristics of the social networks was 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 $P = 0.05$ 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 Bonferroni 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 (Perneger 1998; Nakagawa 2004).

Conclusions with respect to the correlations with $P < 0.05$ 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 *et al.* 2008), in particular a 'good marriage' (Gove *et al.* 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 *et al.* 1994; Lunsky 2006; Ferlander 2007).

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 *et al.* 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.

Acknowledgements

We would like to thank all of those who participated in this research and the students who helped collect the data. We are further grateful to Kim van den Bogaard, Noud Frielink, Joke van der Meer, Jody Sohier and Anne Vereijken for their support during various phases of the research project.

References

- Abbott S. & McConkey R. (2006) The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities* **10**, 275–87.
- Amado A. N., Stancliffe R. J., McCarron M. & McCallion P. (2013) Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and developmental disabilities* **51**, 360–75.
- van Asselt-Goverts A. E., Embregts P. J. C. M., Hendriks A. H. C., Vereijken A., Frielink N., van den Bogaard K. *et al.* (2012) *Handleiding Maastrichtse Sociale Netwerk Analyse voor mensen met een Verstandelijke Beperking [Manual Maastricht Social Network Analysis for People with Intellectual Disabilities (MSNA-ID)]*. HAN University of Applied Sciences, Nijmegen.
- van Asselt-Goverts A. E., Embregts P. J. C. M. & Hendriks A. H. C. (2013) Structural and functional characteristics of the social networks of people with mild intellectual disabilities. *Research in Developmental Disabilities* **34**, 1280–8.
- van Asselt-Goverts A. E., Embregts P. J. C. M., Hendriks A. H. C. & Frielink N. (2014) Experiences of support staff with expanding and strengthening social networks of people with mild intellectual disabilities. *Journal of Community & Applied Social Psychology* **24**, 111–24.

- Baars H. M. J. (1994) *Sociale netwerken van ambulante chronische patiënten (proefschrift) [Social networks of ambulatory chronic psychiatric patients (dissertation)]*. University of Limburg, Maastricht.
- Barrington-Leigh C. P. (2009) *Geography, reference groups, and the determinants of life satisfaction*. Thesis. The University of British Columbia, Vancouver.
- Biegel D. E., Tracy E. M. & Corvo K. N. (1994) Strengthening social networks: Intervention strategies for mental health case managers. *Health and Social Work* **19**, 206–16.
- Bramston P., Chipuer H. & Pretty G. (2005) Conceptual principles of quality of life: an empirical exploration. *Journal of Intellectual Disability Research* **49**, 728–33.
- Campo S. F., Sharpton W. R., Thompson B. & Sexton D. (1997) Correlates of the quality of life of adults with severe or profound mental retardation. *Mental Retardation* **35**, 329–37.
- Cram J. M. & Nieboer A. P. (2012) Longitudinal study of parents' impact on quality of life of children and young adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **25**, 20–8.
- Cummins R. A. (1995) On the trail of the gold standard for subjective well-being. *Social Indicators Research* **35**, 179–200.
- Cummins R. A. (2002) Proxy responding for subjective well-being: a review. *International Review of Research in Mental Retardation* **25**, 183–207.
- Cummins R. A. (2005) Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research* **49**, 699–706.
- Dolan P., Peasgood T. & White M. (2008) Do we really know what makes us happy? A review of the economic literature on the factors associated with subjective well-being. *Journal Of Economic Psychology* **29**, 94–122.
- Duvdevany I. & Arar E. (2004) Leisure activities, friendships, and quality of life of persons with intellectual disability: foster homes versus community residential settings. *International Journal of Rehabilitation Research* **27**, 289–96.
- Emerson E. & Hatton C. (2008) Self-reported well-being of women and men with intellectual disabilities in England. *American Journal on Mental Retardation* **113**, 143–55.
- Ferlander S. (2007) The importance of different forms of social capital for health. *Acta Sociologica* **50**, 115–28.
- Forrester-Jones R., Carpenter J., Coolen-Schrijner P., Cambridge P., Tate A., Beecham J. *et al.* (2006) The Social networks of people living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities* **19**, 285–95.
- Gove W. R., Hughes M. & Briggs Style C. (1983) Does marriage have positive effects on the psychological well-being of the individual? *Journal of Health and Social Behavior* **24**, 122–31.
- Gregory N., Robertson J., Kessissoglou S., Emerson E. & Hatton C. (2001) Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports. *Journal of Intellectual Disability Research* **45**, 279–91.
- Hermesen M. A., Embregts P. J. C. M., Hendriks A. H. C. & Frielink N. (2014) The human degree of care. Professional loving care for people with a mild intellectual disability: an explorative study. *Journal of Intellectual Disability Research* **58**, 221–32.
- Hoekman J., Douma J. C. H., Kersten M. C. O., Schuurman M. I. M. & Koopman H. M. (2001) IDQOL – Intellectual Disability Quality of Life. De ontwikkeling van een instrument ter bepaling van de 'kwaliteit van bestaan' van mensen met een verstandelijke beperking [The development of an instrument to assess the quality of life of people with intellectual disabilities]. *Nederlands Tijdschrift voor Zorg aan verstandelijk gehandicapten* **27**, 207–24.
- Jahoda A., Wilson A., Stalker K. & Cairney A. (2010) Living with stigma and the self-perceptions of people with mild intellectual disabilities. *The Journal of Social Issues* **66**, 521–34.
- de Jong P. & Berg I. K. (2008) *Interviewing for Solutions*, 3rd edn. Thomson Brooks/Cole, Belmont.
- Kamp Dush C. M. & Amato P. R. (2005) Consequences of relationship status and quality for subjective well-being. *Journal of Social and Personal Relationships* **22**, 607–27.
- Lippold T. & Burns J. (2009) Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research* **53**, 463–73.
- Lunsky Y. (2006) Individual differences in interpersonal relationships for persons with mental retardation. In: *International Review of Research in Mental Retardation*, Vol. 31 (ed. H. N. Switzky), pp. 117–61. Elsevier, San Diego.
- Lunsky Y. & Benson B. A. (1997) Reliability of ratings of consumers with mental retardation and their staff on multiple measures of support. *American Journal on Mental Retardation* **102**, 280–4.
- Lunsky Y. & Benson B. A. (2001) Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability. *Journal of Intellectual Disability Research* **45**, 106–14.
- Miller S. M. & Chan F. (2008) Predictors of life satisfaction in individuals with intellectual disabilities. *Journal of Intellectual Disability Research* **52**, 1039–47.
- van de Mortel T. F. (2008) Faking it: social desirability response bias in self-report research. *Australian Journal of Advanced Nursing* **25**, 40–8.

- Nakagawa S. (2004) A farewell to Bonferroni: the problems of low statistical power and publication bias. *Behavioural Ecology* **15**, 1044–5.
- Nota L., Soresi S. & Perry J. (2006) Quality of life in adults with an intellectual disability: the Evaluation of Quality of Life Instrument. *Journal of Intellectual Disability Research* **50**, 371–85.
- Perneger T. V. (1998) What's wrong with Bonferroni adjustments. *British Medical Journal* **316**, 1236–8.
- van Puyenbroeck J. & Maes B. (2009) The effect of reminiscence group work on life satisfaction, self-esteem and mood of ageing people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **22**, 22–33.
- Robertson J., Emerson E., Gregory N., Hatton C., Kessissoglou S., Hallam A. *et al.* (2001) Social networks of people with mental retardation in residential settings. *Mental Retardation* **39**, 201–14.
- Roeleveld E., Embregts P., Hendriks L. & van den Bogaard K. (2011) Zie mij als mens! Noodzakelijke competenties voor begeleiders volgens mensen met een verstandelijke beperking. [See me as a person! Essential competencies for staff members according to people with intellectual disabilities]. *Orthopedagogiek: Onderzoek en Praktijk* **50**, 195–207.
- Schalock R. L. (2004) The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research* **48**, 203–16.
- Schmidt S., Power M., Green A., Lucas-Carrasco R., Eser E., Dragomirecka E. *et al.* (2010) Self and proxy rating of quality of life in adults with intellectual disabilities: results from the DISQOL study. *Research in Developmental Disabilities* **31**, 1015–26.
- Stalker K., Jahoda A., Wilson A. & Cairney A. (2011) 'It's like an itch and I want to get it away but it's still there': understandings and experiences of anxiety and depression among young people with intellectual disabilities. *Scandinavian Journal of Disability Research* **13**, 311–26.
- Stenfert Kroese B., Hussein H., Clifford C. & Ahmed N. (2002) Social support networks and psychological well-being of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **15**, 324–40.
- Taylor J. L. (2002) A review of the assessment and treatment of anger and aggression in offenders with intellectual disability. *Journal of Intellectual Disability Research* **46**, 57–73.
- Verdonschot M. M. L., de Witte L. P., Reichrath E., Buntinx W. H. E. & Curfs L. M. G. (2009) Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research* **53**, 303–18.
- Verdugo M. A., Schalock R. L., Keith K. D. & Stancliffe R. J. (2005) Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research* **49**, 707–17.
- Verdugo M. A., Navas P., Gómez L. E. & Schalock R. L. (2012) The concept of quality of life and its role in enhancing human rights in the field of intellectual disabilities. *Journal of Intellectual Disability Research* **56**, 1036–45.

Accepted 4 June 2014