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Kamstra, A.; van der Putten, A. A. J.; Post, W. J.; Vlaskamp, C.

Published in:
Journal of Applied Research in Intellectual Disabilities

DOI:
[10.1111/jar.12115](https://doi.org/10.1111/jar.12115)

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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2015

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Kamstra, A., van der Putten, A. A. J., Post, W. J., & Vlaskamp, C. (2015). Informal social networks of people with profound intellectual and multiple disabilities: Relationship with age, communicative abilities and current living arrangements. *Journal of Applied Research in Intellectual Disabilities*, 28(2), 159-64. <https://doi.org/10.1111/jar.12115>

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BRIEF REPORT**Informal Social Networks of People with Profound Intellectual and Multiple Disabilities: Relationship with Age, Communicative Abilities and Current Living Arrangements**A. Kamstra^{*†}, A. A. J. van der Putten^{*†}, W. J. Post^{*} and C. Vlaskamp^{*}^{*}Department of Special Needs Education and Child Care, University of Groningen, Groningen, the Netherlands; [†]'s Heeren Loo, Amersfoort, the Netherlands**Accepted for publication** 12 June 2014

Background People with profound intellectual and multiple disabilities (PIMD) have limited informal social contacts. Research to determine the factors which can positively influence establishing sound informal social contacts is required.

Materials and Methods Regression analysis for 200 people with PIMD was used to analyse how age, communicative abilities and current living arrangements were related to the number and frequency of their contacts.

Results Only age was negatively related to both the number and frequency of social contacts. Current living

arrangements related only to the frequency of contacts. Communicative abilities related to neither.

Conclusions Like people with intellectual disabilities, age and living arrangements are related to the informal social networks of people with PIMD. However, for people with PIMD, these networks are already more limited. Therefore, professionals need to be attentive to the maintenance and/or expansion of the social networks of people with PIMD at an early stage.

Keywords: age, living arrangements, profound intellectual disabilities, social contacts, social networks

Introduction

It is widely acknowledged that having social contacts is an important aspect of the quality of life of people with intellectual disabilities (Schalock & Verdugo 2002), which is equally true for people with profound intellectual and multiple disabilities (PIMD) (Petry *et al.* 2005). All social contacts together form the social network of a person. Social networks have structural and functional characteristics (Buysse 1997; Lippold & Burns 2009). The structural characteristics contain the amount of social contact persons, the frequency of the contacts, the type of relation between the network owner and member and the type of contacts. The functional characteristics are the purposes of the contacts, coming from both informal and formal sources

(Forrester-Jones *et al.* 2006; Bigby 2008; Heaney & Israel 2008). These two sources can be distinguished by the fact that formal contact persons are paid (professionals) and have a clear job description. Informal contact persons (non-professionals) all have their own motives for providing support to a person with PIMD. Baumeister & Leary (1995) stated that all people generally have the internal drive to obtain and maintain at least a few long-term, positive and special contacts with others. If this is lacking, it can result in severe deprivation with negative effects.

Usually, people without disabilities show initiative in establishing and maintaining their social contacts. This is not the case in people with PIMD. Throughout their lives, they are totally dependent on others in almost every aspect of daily living, including establishing and

maintaining informal social contacts (Petry *et al.* 2005; Nakken & Vlaskamp 2007; Hostyn & Daelman 2011). When living at home, parents facilitate these contacts. But when reaching adulthood, most people with PIMD in the Netherlands will move out-of-home to a living arrangement. This will have impact on the social network of people with PIMD. Recent research provided the overall conclusion that informal social networks of people with PIMD, not living with their parents, are small. On average, they have contact with only five informal contact persons per year, of which 80% is a family member (Kamstra *et al.* in press).

Previous research in the general population of people with ID has shown that specific factors such as age and current living arrangements are associated with the size of the social network and the frequency of contacts with non-professional others (Baker *et al.* 1993; Blacher *et al.* 1999; Robertson *et al.* 2001; McConkey 2007; Bigby 2008). Given the severity of the disabilities and the heterogeneity of people with PIMD, it is doubtful whether these results can be generalized. Moreover, the limited communicative abilities of this group could be related to the size of the informal social network and frequency of the contacts: a person who is able to use words will interact more ably than a person who is only able to use body language.

In order to be able to improve the informal social network of persons with PIMD, more information is needed about factors related to the size of the informal social network and the frequency of the contacts. Therefore, the question addressed in this study is: To what extent is the informal social network size, and the frequency of informal social contacts of people with PIMD related to age, communicative abilities and current living arrangements?

Materials and Methods

Participants and setting

A total of 13 living arrangements in the Netherlands participated. After initial approval of the research proposal by the organization of these facilities, a total of 375 parents or legal representatives of people with PIMD were addressed to obtain informed consent. Written informed consent was received from 54.7% of parents or legal representatives. This yielded 205 people with PIMD about whom information was gathered. All these people had a profound intellectual disability with an estimated developmental age below 2 years, and a severe or profound motor disability. They also had

sensory disabilities, especially visual or auditory (Nakken & Vlaskamp 2007), and difficulties in signalling or communicating their emotional responses or needs (Petry *et al.* 2005; Schuengel *et al.* 2010). These disabilities and difficulties lead to serious limitations in their daily lives and to limitations in their interactions with others (Hostyn & Daelman 2011).

Two direct support persons (DSPs) per person with PIMD were asked to participate in an interview: each had to have known the person with PIMD for at least 6 months. A total of 410 DSPs were interviewed: these DSPs knew the people with PIMD an average of 99 months each (range: 6–480, SD = 85.13). All DSPs were formal contact persons and therefore not included in the informal social network.

Measures

Data on the informal network size and the frequency of contacts were collected using an interview with semi-closed retrospective questions. Questions were asked about informal social network size over the preceding 12 months and the estimated total number of contacts in a year between the informal contact person and the person with PIMD, regardless of the duration of that contact. In case of disagreement between the DSPs about an answer, they were asked to discuss the answer and achieve consensus.

Age was measured as a continuous variable in years. Communicative abilities were categorized as: (i) body movement, face or eye movement; (ii) vocalizations (i.e. laughing or shouting); and (iii) symbolic forms (i.e. pointing or words) (adapted from Marschik *et al.* 2012). Each communicative ability category was scored with a yes or no. The current living arrangements were categorized as (i) campus-style settings: houses accommodating about six to eight people, with up to 100 people on the same site and staff available on a 24-h basis; and (ii) small community homes: living in groups of around six people in a house owned by the service provider, with staff available 24 h a day and located within the community (McConkey 2007).

Analysis

First, descriptive statistics of the variables were calculated. Each participant's sum communicative ability score was calculated, ranging from 1 to 3. The total of all informal contact persons per person with PIMD formed the size of the social network. The 205 participants had an average of 5.1 informal contact

persons, (SD = 4.2) of whom five appeared to have 20 or more informal contact persons. No common characteristics were found for these five participants concerning age, communicative abilities and current living scheme. The present authors consider them as a unique group, and the choice was made to leave these participants out of the analyses. Otherwise, results will be biased because of their influence on the analysis. Therefore, all calculations concerning the size of the informal network are performed on the remaining 200 participants.

First a regression analysis was performed with size of social network as dependent variable and age, communicative abilities and current living scheme as explanatory variables. Significant related independent variables ($P < 0.10$) and interactions between variables were included in the model.

The mean of the contacts per person with PIMD was calculated as dependent variable 'frequency of the contacts'. Because the frequency data were positively skewed, the mean frequency of contacts was divided into fitting categories (times per year): 0–5, 6–11, 12–23, 24–51 and >51, based on Baker *et al.* (1993). Spearman correlation coefficient and Cramers's V were calculated to determine bivariate relations. Significant variables ($P < 0.10$) were included as explanatory variables in an ordinal logistic regression model.

Results

Table 1 lists the descriptive data for the full sample.

Informal social network size

Age was the only variable significantly associated with the size of the network. Simple linear regression showed that age explained a significant amount of the variance in the size of the social network ($R^2 = 0.09$, $F(1.198) = 19.23$, $P < 0.0001$). According to this model, the number of informal contact persons decreases as the person with PIMD ages ($\beta = -0.06$, $t = -4.39$, $P < 0.0001$). Communicative abilities and living arrangements were not significantly related to the informal social network size. However, including these effects together with their interaction provided non-significant, but interesting interaction effects, as can be seen in Figure 1. The 95% confidence interval for people with three communicative abilities in a campus setting was 2.61–5.74 ($n = 15$), and 4.90–8.99 ($n = 9$) for people living in a small community home. People who had three communicative abilities and were living in a small community home had the most

Table 1 Descriptive statistics: percentage or mean (range; SD) $N = 200$

	Mean (range; SD)	Percentage
Age in years	48.07 (13–79; 15.84)	
Gender: male		44.0
Communicative abilities		
1		41.0
2		47.0
3		12.0
Current living arrangements		
Small community homes		28.5
Campus-style setting		71.5
Size of network	4.69 (0–16, 3.21)	
Frequency contact (times per year)		
0–5		26.5
6–11		20.5
12–23		21.5
24–51		18.0
>52		13.5

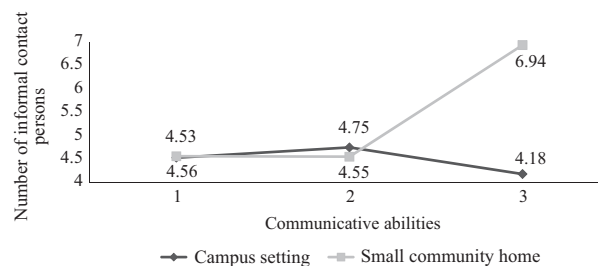


Figure 1 Estimated number of informal contact persons by communicative abilities and living arrangements.

informal contact persons compared with the remaining groups.

Frequency of the contacts

Bivariate analyses showed that age ($r_s = -0.57$, $P < 0.0001$) and current living arrangements ($V = 0.21$, $P = 0.072$) are significantly associated with contact frequency. Including these as explanatory variables in an ordinal regression provided a satisfactory model ($\chi^2 = 77.70$; $P < 0.0001$). No significant interaction effects were found. The assumption of parallel lines was not violated ($\chi^2 = 7.28$; $P = 0.30$). The results presented in Table 2 show that age and current living arrangements are negatively related. Being older and living in a campus environment increases the chances of lower frequency of contact.

Table 2 Ordinal logistic regression results concerning frequency of contact with age and living arrangements ($N = 200$)

	Estimate	SE	Sig	95% CI
Frequency of contact, times per year				
0–5	–5.25	0.57	<0.0001	–6.36 to –4.13
6–11	–4.07	0.53	<0.0001	–5.10 to –3.04
12–23	–2.89	0.48	<0.0001	–3.83 to –1.94
24–51	–1.55	0.46	<0.001	–2.45 to –0.65
Age in years	–0.07	0.01	<0.0001	–0.09 to –0.06
Living arrangements				
Campus-style setting	–0.57	0.29	0.049	–1.14 to 0

Discussion

The aim of this study was to determine whether the age, communicative abilities and current living arrangements of people with PIMD are related to the size of their social networks and their contact frequency. Social network size appeared to be smaller for older people with PIMD, who also have a lower contact frequency. Living in a campus environment also relates to a lower contact frequency compared with living in a small community home. Communicative abilities are neither significantly related to social network size nor to contact frequency. These results are aligned to the results of other studies of people with intellectual disabilities in general (Baker *et al.* 1993; Blacher *et al.* 1999; Robertson *et al.* 2001; McConkey 2007; Bigby 2008).

Our study has some methodological restrictions that need to be taken into account when interpreting its results. Due to the communicative limitations of the people with PIMD, data were collected by proxy. To limit the risks of incorrect or incomplete data, two DSPs were interviewed who had, if they disagreed, to reach consensus about the answers given. Consensus was always reached. Age explained <10% of the variance in the size of the social network. Other factors that can possibly explain the variance in the social networks of people with PIMD are time living in a living arrangement (Blacher *et al.* 1999) and strength of the relationships (Bigby *et al.* 2009). Explanations can also be sought in the characteristics of individual network members; for instance, the physical distance to the living arrangement, age, religion, marital status or socioeconomic status of the network member (Baker *et al.* 1993). Also environmental factors as: staffing, organizational hygiene and management are known to

be related to care practises (Mansell *et al.* 2008) and therefore can possibly contribute to explaining the structure of social networks. Communicative abilities and living arrangements showed a non-significant interaction effect. Calculations were performed without the five participants with a very large network size. When the present authors included these participants in the analyses, the interaction effect for communicative abilities and living arrangements became significant. Given that this result is biased, as the model assumption of homoscedasticity was violated, it is still important to realize that having more communicative abilities and living in a community home seems to lead to a larger network size. Including the five participants in the results concerning the frequency had no effects on the significance. Differences in effect size appeared to be minimal with a maximum of five hundredths. However, participants with large network size are interesting as a group as a whole, where they might provide useful information about the effective factors in social networks.

The trends observed in the social networks of people with PIMD are similar to the people with intellectual disabilities group. However, the social networks of people with PIMD are, in general, already small and restricted to relatives (Kamstra *et al.* in press). Networks only seem to shrink as time goes by and no new members appear to be added. This implication supports the conclusions by Bigby (1997) who stated that ‘the lack of intergenerational members, shared relationships and situation-specific friendships makes their (older people with intellectual disabilities) informal networks vulnerable to shrinkage’. Furthermore, medical developments have resulted in a longer life expectancy for people with PIMD, which makes it more likely for them to outlive their parents. These parents fear the moment they will no longer be there for their child (Luijkx & Vlaskamp 2012). People with PIMD are also unable to reach out to others alone, so the environment needs to be proactive in this sense, starting at an early age and continuing throughout the person’s life. Therefore, planning for ‘replacements’ of parents needs to happen actively (Bigby 1997) in a careful collaboration between informal and formal contact persons. Otherwise, positive changes will not occur and quality of life can be compromised. Early reflection on the composition of the social networks of young people with PIMD is necessary to preventively expand their networks or to fill the gaps that can open over the years. The model for early intervention and family support (Dunst 2000) can be used as a starting point to do so. Special attention should be paid to creating meaningful relationships

within these networks, for instance by understanding what makes interaction meaningful, sharing information with different network members or using social interactions as an activity (Johnson *et al.* 2010, 2012a). People with PIMD need others willing to invest time in them and to develop successful interactions and thereby meaningful relationships. The relationship processes model as provided by Johnson *et al.* (2012b) may be useful to analyse the current relationships and assist the environment to develop skills in creating and supporting meaningful relationships for persons with PIMD. If this can be achieved, people with PIMD can profit greatly from these social relationships, which will add to their perceived quality of life (Petry *et al.* 2005; Nakken & Vlaskamp 2007; Hostyn & Maes 2009). These meaningful relationships can facilitate social inclusion (Abbott & McConkey 2006; McConkey 2007; Bigby *et al.* 2009; Johnson *et al.* 2010) and are known to prevent loneliness and negative health effects (Baumeister & Leary 1995). The role of the professional in 'managing' social networks and the meaningful relationships within them should also be explored further.

Correspondence

Any correspondence should be directed to Aafke Kamstra, Grote Rozenstraat 38, 9712 TJ Groningen, the Netherlands (e-mail: aafke.kamstra@rug.nl).

References

- Abbott S. & McConkey R. (2006) The barriers to social inclusion as perceived by persons with intellectual disabilities. *Journal of Intellectual Disabilities* **10**, 275–287.
- Baker B. L., Blacher J. & Pfeiffer S. (1993) Family involvement in residential treatment of children with psychiatric disorder and mental retardation. *Hospital & Community Psychiatry* **44**, 561–566.
- Baumeister R. F. & Leary M. R. (1995) The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin* **117**, 497–529.
- Bigby C. (1997) When parents relinquish care: informal support networks of older persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **10**, 333–344.
- Bigby C. (2008) Known well by no-one: trends in the informal social networks of middle-aged and older persons with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability* **33**, 148–157.
- Bigby C., Clement T., Mansell J. & Beadle-Brown J. (2009) 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': staff attitudes about the applicability of disability policies to persons with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research* **53**, 363–376.
- Blacher J., Baker B. L. & Feinfield K. A. (1999) Leaving or launching? continuing family involvement with children and adolescents in placement. *American Journal on Mental Retardation* **104**, 452–465.
- Buyse W. H. (1997) Personal social networks and behavior problems in adolescence. an explorative study in three examples: A residential sample, a day treatment and a reference sample. Doctoral Dissertation, Leiden University, Leiden.
- Dunst C. J. (2000) Revisiting "rethinking early intervention". *Topics in Early Childhood Special Education* **20**, 95–104.
- Forrester-Jones R., Carpenter J., Coolen-Schrijner P., Cambridge P., Tate A., Beecham J., Hallam A., Knapp M. & Wooff D. (2006) The social networks of persons with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities* **19**, 285–295.
- Heaney C. A. & Israel B. A. (2008) Social networks and social support. In: *Health Behavior and Health Education: Theory, Research and Practice*. 4th edn (eds K. Glanz, B. K. Rimer & K. Viswanath), pp. 189–210. Jossey-Bass, San Francisco.
- Hostyn I. & Daelman M. (2011) Kwaliteitsvolle interacties. In: *Ondersteuning van mensen met ernstige meervoudige beperkingen. Handvaten voor een kwaliteitsvol leven* (eds B. Maes, C. Vlaskamp & A. Penne), pp. 102–125. Acco, Leuven.
- Hostyn I. & Maes B. (2009) Interaction between persons with profound intellectual and multiple disabilities and their partners: a literature review. *Journal of Intellectual & Developmental Disability* **34**, 296–312.
- Johnson H., Douglas J., Bigby C. & Iacono T. (2010) The pearl in the middle: a case study of social interactions in an individual with a severe intellectual disability. *Journal of Intellectual and Developmental Disability* **35**, 175–186.
- Johnson H., Douglas J., Bigby C. & Iacono T. (2012a) Social interaction with adults with severe intellectual disability: having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities* **25**, 325–341.
- Johnson H., Douglas J., Bigby C. & Iacono T. (2012b) A model of processes that underpin positive relationships for adults with severe intellectual disability. *Journal of Intellectual and Developmental Disability* **37**, 324–336.
- Kamstra A., van der Putten A. A. J. & Vlaskamp C. (in press) The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*.
- 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**, 463–473.

- Luijkx J. & Vlaskamp C. (2012) *Toch is het een goede keus geweest. Ervaringen van ouders van kinderen met ernstige meervoudige beperkingen*. Garant uitgevers, Antwerpen.
- Mansell J., Beadle-Brown J., Whelton B., Beckett C. & Hutchinson A. (2008) Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **21**, 398–413.
- Marschik P. B., Kaufmann W. E., Einspieler C., Bartl-Pokorny K. D., Wolin T., Pini G., Budimirovic D. B., Zappella M. & Sigafos J. (2012) Profiling early socio-communicative development in five young girls with the preserved speech variant of Rett syndrome. *Research in Developmental Disabilities* **33**, 1749–1756.
- McConkey R. (2007) Variations in the social inclusion of persons with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research* **51**, 207–217.
- Nakken H. & Vlaskamp C. (2007) A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities* **4**, 83–87.
- Petry K., Maes B. & Vlaskamp C. (2005) Domains of quality of life of persons with profound multiple disabilities: the perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities* **18**, 35–46.
- Robertson J., Emerson E., Gregory N., Hatton C., Kessissoglou S., Hallam A. & Linehan C. (2001) Social networks of persons with mental retardation in residential settings. *Mental Retardation* **39**, 201–214.
- Schalock R. L. & Verdugo M. A. (2002) *Handbook on Quality of Life for Human Service Practitioners*. American Association on Mental Retardation, Washington.
- Schuengel C., Kef S., Damen S. & Worm M. (2010) 'People who need people': attachment and professional caregiving. *Journal of Intellectual Disability Research* **54**, 38–47.