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## Perspectives of people with intellectual disability about their family networks: A comparison study with key support worker proxy reports

Tess Tournier <sup>a,b</sup>, Alexander H. C. Hendriks <sup>c</sup>, Andrew Jahoda <sup>d</sup>, Richard P. Hastings <sup>e,f</sup>,  
Sanne A. H. Giesbers <sup>a</sup> and Petri J. C. M. Embregts <sup>a</sup>

<sup>a</sup>Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands; <sup>b</sup>ASVZ, Sliedrecht, The Netherlands; <sup>c</sup>School of Pedagogical and Educational Science, Faculty of Social Sciences, Radboud University, Nijmegen, The Netherlands; <sup>d</sup>Institute of Health and Wellbeing, University of Glasgow, Glasgow, UK; <sup>e</sup>Centre for Educational Development, Appraisal and Research, University of Warwick, Coventry, UK; <sup>f</sup>Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, School of Clinical Sciences at Monash Health, Monash University, Clayton, Australia

### ABSTRACT

**Background:** The Family Network Method – Intellectual Disability (FNM-ID) was used to compare perspectives of people with mild intellectual disability and their support workers on family networks of people with intellectual disability.

**Method:** 138 participants with mild intellectual disability and support workers were interviewed, using the FNM-ID. Paired *t*-tests were used to examine differences in perspectives. Multiple regression analyses were used to examine divergence in perspectives.

**Results:** People with mild intellectual disability perceived their family networks to be larger and to provide more support than support workers did. Living in a residential setting and having higher levels of externalising behaviour were associated with differences in perspectives, whereas a higher level of internalising behaviour was associated with more similar views.

**Conclusions:** Individuals with intellectual disability and support workers are unlikely to provide the same information about family networks of people with mild intellectual disability. Behavioural and emotional problems were associated with divergence in perspectives.

### KEYWORDS

Social network analysis; emotional support; proxy-report; self-report; mental health; mild intellectual disability

Family members have a significant role in the lives of people with intellectual disability. Their unconditional love, lifetime commitment, and emotional closeness bring significant and unique qualities to their relationships (Bigby & Fyffe, 2012). In some cases, people with intellectual disability do not live with their family but in community or residential care (Brown et al., 2011), which has implications for their relationship with family if they are more distant from their significant others. Support staff may have, therefore, a significant role to help maintain the links people with intellectual disability have with their family members (McConkey & Collins, 2010).

To be able to carry out this supporting task, staff need to understand the existing family network and family ties of individuals they support. Knowledge about family relationships of people with intellectual disability is crucial as it is associated with positive outcomes in assisting the people with intellectual disability with developing, maintaining, and enhancing relationships (Van Asselt-Goverts et al., 2015). Therefore, knowing who are

represented in the family networks is significant information for support staff, to have a good understanding of the social needs and preferences of people with intellectual disability. However, there is uncertainty whether support staff are always well informed about the families of people with intellectual disability, or know who the individual with intellectual disability has contact with (Bigby, 2008).

In intellectual disability research, practitioners and researchers often rely on proxy reports partly because it can be more challenging to obtain self-reported information (Scott & Haverkamp, 2018) due to, among other factors, the cognitive demands of providing self-report information (Bertelli et al., 2017; Fujiura, 2012). Working with proxy-reports to obtain data about people with intellectual disability may be a partial solution to the self-report problem. However, the data may be limited as it is more difficult for a proxy to report on the personal perspectives of another individual on topics such as mental health, quality of life, and relationships. For

**CONTACT** Tess Tournier  [t.tournier@uvt.nl](mailto:t.tournier@uvt.nl) [t.tournier@tilburguniversity.edu](mailto:t.tournier@tilburguniversity.edu)

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example, Koch et al. (2015) compared self- and proxy-reports of the Quality of Life (QoL) of 102 people with intellectual disability, using the World Health Organization Quality of Life-BREF (Skevington et al., 2004). Results showed that people with intellectual disability scored their QoL significantly higher compared to the proxy reports in all five domains, with large effect size differences in the psychological and social domain and medium sized differences in the physical, environment, and disability domains. Schmidt et al. (2010) used the same measure and found significant but only moderate associations for the five life domains, including the subjective domains, between the self- and proxy QoL-assessment of 614 adults with intellectual disability and their proxies (including professional caregivers).

There is also a growing body of literature that highlights the discrepancies between self- and proxy reports for other subjective data in the population of people with intellectual disability (Lunsky & Benson, 1997; Lunsky & Bramston, 2006; Scott & Havercamp, 2018). Lunsky and Benson (1997) compared the perspectives of people with intellectual disability and support staff on social support. Staff rated the support people with intellectual disability got from family or from staff and friends significantly lower than people with intellectual disability themselves. Scott and Havercamp (2018) found that staff rated friendship support significantly lower than family or staff support while self-report of people with intellectual disability indicated that friends provided as much support as staff or family. Lunsky and Bramston (2006) showed that staff rated the stress people with intellectual disability experience higher than did people with intellectual disability themselves.

Despite the possible divergence between proxy informants and the self-report of the person with intellectual disability, proxy responses are commonly used in intellectual disability research (Scott & Havercamp, 2018). Key support workers may be used as proxy informants because they are familiar with the person with intellectual disability, which may give them more confidence to report about the person's life experiences and preferences (Cummins, 2002). Although researchers have examined self-proxy report agreement about social support, research has rarely focused on other dimensions of family relationships, despite the fact that family has a significant role in the lives of people with intellectual disability (Bigby & Fyffe, 2012). We were not able to find studies comparing self-reports about family relationships with staff proxy-reports, but there has been research comparing how people with intellectual disability viewed their family networks with family members' views. Widmer et al. (2010) compared the perceptions of people with intellectual disability and psychiatric disorders and their family members on the

family relationships of the individuals with intellectual disability. The family networks were measured using the Family Network Method (FNM) to assess the characteristics of the family network and the perceived emotional support within the whole family network (Widmer et al., 2013). Widmer et al. (2010) found that both respondent groups perceived that the person with intellectual disability both received and gave emotional support in their family network. However, family members thought the individuals had smaller family networks and less emotional support within the family network than did the participants with intellectual disability themselves.

The FNM was adapted by Giesbers et al. (2019) into the Family Network Method – Intellectual Disability (FNM-ID) to measure family networks of people with intellectual disability and to estimate relationships among all the family members in terms of reciprocal emotional support. The term emotional support refers to love and caring, sympathy and understanding, and/or esteem and value from others (Thoits, 1995). As the FNM-ID can be completed by different stakeholders, including people with intellectual disability themselves, professionals and family, the aim of this study was to examine if support staff's own views agree with people's own views about their family networks.

In existing research on staff as proxies and self-reports on personal experiences and perspectives of people with intellectual disability, differences have been noted but the factors that might contribute to, or are associated with, divergence or convergence of ratings have hardly been examined. We found one study of Schmidt et al. (2010) which showed it was possible to predict the differences between perspectives on QoL of people with intellectual disability and proxies (relative or support worker) by two variables. First, when the proxy knew the individual with intellectual disability well, their perspectives on QoL were more similar. Second, when the severity of disability was higher (measured with the World Health Organization Disability Assessment Schedule; Üstün & World Health Organization, 2010), the smaller were the differences between the individual with intellectual disability and the proxy report.

The second aim of the current study was to consider individual characteristics or factors, which might make it more or less difficult for support staff to develop insight into people's perspectives regarding their family networks. Four factors were selected: gender, living situation, mental health, and challenging behaviour. Gender was selected because men tend to hold more instrumental attitudes, whereas women hold more emotionally responsive attitudes, and seem to disclose emotions more easily (Bakker et al., 2002; Ogus et al., 1990). Thus females with intellectual disability may share

more emotional information with support staff, potentially making staff better informed.

Living situation was included because this may have influence on the amount of support a person receives. We included participants who lived more independently in the community, in group homes or clusters of apartments with outreach support for a part of each day but where support staff were available at other times if necessary. We also included participants who lived in a residential facility, a site with multiple group homes for people with intellectual disability, and where support staff present all the time. This has implications for the frequency of contact someone has with support staff. When people have regular contact with each other, and know each other for a longer period, proxies seem to be better able to act as a proxy reporter (Schmidt et al., 2010).

Mental health and challenging behaviour were included as possible correlates of divergence in perspectives because both factors may affect the relationship between the individual and their support staff. Challenging behaviour of people with intellectual disability towards support staff or themselves can raise strong feelings for support staff, such as annoyance, anger, fear, sadness, and despair (Hastings & Remington, 1995; Bromley & Emerson, 1995). These unpleasant feelings may lead to avoidance and a depersonalised attitude towards people with intellectual disability and challenging behaviour (Hastings & Brown, 2002; Mitchell & Hastings, 2001). Therefore, challenging behaviour may be associated with a more distant relationship between the support worker and the individual with intellectual disability, which might adversely affect staff knowledge of the individual's family relationships. Alternatively, support staff and family may work more closely together in the support of individuals with intellectual disability and challenging behaviour. Family members may, for example, provide support staff with information about changes in the behaviour of their relative (Bright et al., 2018). Family members might also be involved in assessing risks and organising visits home. This closer collaboration could contribute to a better understanding of the family networks by support staff. Mental health issues can also lead to avoidant or stigmatising behaviour from professionals towards people with intellectual disability (Araten-Bergman & Werner, 2017; Ouellette-Kuntz et al., 2003), which may also affect the closeness of the relationship between an individual with intellectual disability and their support worker and divergence in perspectives about family support.

In the current study, the perspectives of people with intellectual disability and their key support workers on

the family networks of people with intellectual disability were compared. We explored: (1) the characteristics of the family networks of people with intellectual disability, by examining both their own perspective and the perspective of their key support workers using an adapted version of Widmer's (Widmer et al., 2013) Family Network Method (the FNM-ID; Giesbers et al., 2019), and (2) divergence in perceptions of the person with intellectual disability and their key support worker associated with the presence of internalising and/or externalising behaviour problems, challenging behaviour, gender, and the person's living arrangement.

## Method

### Participants

Participants were people with mild intellectual disability (IQ 50-70;  $n = 138$ ) and their key support workers ( $n = 138$ ). The participants with mild intellectual disability ranged in age between 18 and 40 years ( $M = 28.2$  years;  $SD = 6.14$ ). Most of the participants had a Dutch cultural background ( $n = 127$ , 92.0%), 78 were male (56.5%), and 62 (44.9%) were officially diagnosed by a certified clinician with a psychiatric or developmental disorder, with autism the most common category ( $n = 33$ , 24.1%). Most of the participants lived in a facility in the community ( $n = 116$ , 84.1%), the others lived in a residential facility ( $n = 22$ , 15.9%). Most of the support workers taking part were female (81.2%) and their mean age was 41.9 years (range 23-63 years). The mean length of time that support workers had been working in care was 18.6 years (range 3-45), and 128 participants (92.8%) had received specific training in the field of social work or health care, 82 participants (64.1%) of whom had intermediate vocational training (education which focuses on necessary knowledge and skills for a chosen occupation) and 46 participants (35.9%) of whom had a higher professional education and training (education which focusses on theoretical and practical training or focus on training in academic disciplines).

### Measures

#### Family networks

To measure support in the family networks of people with mild intellectual disability the Family Network Method – Intellectual Disability (FNM-ID; Giesbers et al., 2019) was used. The FNM-ID maps the significant family network and is used to estimate relationships among all the family members in terms of reciprocal emotional support. Participants with mild intellectual

disability as well as their staff member were individually asked about their perception of the family support network of the individual with mild intellectual disability.

For this study, we used four steps from the FNM-ID. The first step is to map the family network of the person with intellectual disability. Participants were asked to provide a list of all individuals whom they considered to be a family member to the person with intellectual disability. The term “family” was deliberately left undefined to identify the participants’ personal definition of family. The second step was to make a selection of family members who were considered to be significant to the participant with intellectual disability from all the listed family members. In the third step, the participant was asked which family members provide support when the participant with intellectual disability feels “out of sorts”. They can make a selection from all the listed family members in step one. In the final step of the method, demographic information (e.g., age, gender, nature of the family tie) on each listed family member were collected.

### *Cognitive ability*

Because IQ scores of the participant were often missing, or obtained using unidentified or outdated IQ tests, a brief screening was carried out to check whether a participant met the inclusion criteria of mild intellectual disability. No Dutch Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler, 2011) was available, and so two subtests (Vocabulary and Matrix Reasoning) of the Dutch Wechsler Adult Intelligence Scale (WAIS-IV-NL; Wechsler, 2012) were administered. These two WAIS-IV-NL subtests correspond with the two-subtest form of the WASI-II. An estimation of IQ scores was made based on the subtest standard scores of the two WAIS-IV subtests. A participant was excluded from the study when both WAIS-IV-NL standard sub-test scores were indicative of a level of cognitive ability above or below the mild intellectual disability range (taking the standard error into account). Participants who scored in the intellectual disability range on only one subtest were included in the study, because people with intellectual disability often have a varied intelligence profile.

### *Behavioural and emotional problems*

The Adult Behaviour Checklist (ABCL; Achenbach & Rescorla, 2003) was used to measure behavioural and emotional problems. This questionnaire examines a broad range of behavioural and emotional problems: anxious/depressed, attention problems, withdrawn, aggressive behaviour, somatic complaints, rule-breaking behaviour, thought problems, intrusive. In the current

study, we used the scores concerning internalising behaviour (i.e., anxious/depressive problems, somatic complaints, and withdrawn behaviour) and externalizing behaviour (aggressive behaviour, rule-breaking behaviour, and intrusive behaviour). The ABCL was completed by a proxy informant; the key support workers. Key support workers were asked to rate how the items had been of the participants over the past 6 months. A 3-point response scale was used, “not true” (0), “somewhat or sometimes true” (1), and “very true or often true” (2). Tenneij and Koot (2007) found that the internal consistency coefficient Cronbach’s alpha of the ABCL scales, for people with intellectual disability, ranged from 0.69 to 0.95 (mean alpha = 0.84). Furthermore they showed that the inter-rater reliability, assessed by the intra class correlation coefficient, ranged from 0.57 to 0.76 (mean = 0.68).

### *Behaviour Problems Inventory*

The Behaviour Problems Inventory-01 (BPI-01) is a questionnaire that was designed to assess challenging behaviours in individuals with intellectual disability. The items fall into one of three subscales: Self-Injurious Behaviour (14 items), Stereotyped Behaviour (24 items), and Aggressive/Destructive Behaviour (11 items). Each item is rated on a frequency scale (0 = never to 4 = hourly), and a severity scale (0 = no problem to 3 = severe problem; Rojahn et al., 2001). In the current study, a working definition of challenging behaviour was used to determine if a participant with intellectual disability had shown significant challenging behaviour during the past two months (Bowring et al., 2017). For the working definition, self-injurious behaviour was determined as challenging if any related item was rated as severe and as occurring at least weekly, or when any related item was rated as moderate but had occurred at least daily. Aggressive–destructive behaviour was determined as challenging either if items were rated as severe and occurred at least weekly, or when the items were rated as moderate but occurred at least daily. Stereotyped behaviour was determined to be challenging if the behaviour occurred at the highest rated frequency (hourly). Participants were then categorised in terms of whether they showed any significant challenging behaviour (one or more of Self-injurious, Aggressive–destructive behaviour, or Stereotypy) or no significant challenging behaviour.

The Dutch version of the BPI-01 has good psychometric properties based on frequency scores. The internal consistency of the total scale as well as of two out of three subscales is good. The internal consistency for the total BPI-01 scale was .89 and for the subscales: Self-Injurious Behaviour .63, Stereotyped Behaviour .85,

and Aggressive/Destructive Behaviour .88 (Dumont et al., 2014). Good intra-class correlations were found for the total scale as well as the subscales of the Dutch version of the BPI-01; the items in the same group resemble each other. The total scale was .93 ( $p < .05$ ), intra-class correlations for the subscales were: Self-Injurious Behaviour .86 ( $p < .05$ ), Stereotyped Behaviour .90 ( $p < .05$ ), and Aggressive/Destructive behaviour .93 ( $p < .05$ ) (Dumont et al., 2014).

### Procedure

Approval was provided by the Ethics Committee of Tilburg University (EC-2015.46). A stratified sampling procedure was carried out within five service providers that offer long-term care to individuals with intellectual disability in the Netherlands. First, the total number of people with mild intellectual disability who met the inclusion criteria was identified for each service provider. Inclusion criteria to participate in the study were: (1) aged 18–40 years, (2) mild intellectual disability (IQ 50–70), and (3) receiving professional support at least once a week for at least 6 months. The limit for inclusion was set at 40 years old, since parents of older individuals with intellectual disability are likely to be elderly and less able to provide support (Bigby, 2008), potentially influencing the study findings. Then, a randomly selected sample of 10% of each service provider was drawn from individuals who met inclusion criteria. Because the group of selected individuals who met inclusion criteria differed in size per service provider, the number of selected participants per service provider varied from 14 to 50.

Participants with mild intellectual disability were approached in consultation with their key support workers. In total, key support workers of the 354 selected individuals with mild intellectual disability were contacted by telephone. During this telephone call the aim and procedure of the study were explained and the researcher did an extra check of the inclusion criteria. An information letter about the study was sent to the key support worker and they were asked to discuss the letter with the selected individual with mild intellectual disability if they wanted to participate in the study. The letter contained information about the aim of the study, the financial reward for participation (ten euro cash), and confidentiality of the data. One hundred and fifty people with mild intellectual disability (42.4%) agreed to take part in the study. The main reason for non-participation was that participants were not interested in taking part in the study (57.4%). In some cases (32.4%), the support worker and/or psychologist advised against participation in the study (e.g.,

because it was expected that talking about the family would be too demanding). The researchers always checked with key support workers if an individual with mild intellectual disability did not have the capacity to decide about participating in the study. Some participants had a legal guardian under Dutch law (a parent or professional) who was then legally empowered to make decisions for the individual with mild intellectual disability. When inviting people with mild intellectual disability to participate in the study, a small group (10.3%) did not participate because their relatives or guardians did not give permission. Legally, we had to comply with the guardian's decision.

An appointment was made to meet with those who agreed to take part in the study. Depending on the participants' preference, the interviews were administered at the participants' home or at an office of the service provider. The first and the fifth author and a research assistant (all psychologists), were qualified to administer all included measures. They carried out the face-to-face interviews, which usually took between 45 min and 1 h. Nine times (6.0% of the cases) a second appointment was necessary to complete the interview, due to concentration difficulties. To put the participant at ease, the interview always started with small talk. Next, a standard consent procedure was followed to make sure the participant was able to give consent (Arscott et al., 1998). After explaining the research project to the participant (both written and verbally), the researcher determined whether the participant could recall the information by asking them five questions: (i) What will I be talking to you about?, (ii) How many times will I be talking to you?, (iii) Are there any good things about talking to me?, (iv) Are there any bad things about talking to me?, (v) What can you do if you decide that you do not want to talk to me anymore? If the participant was unable to answer the questions, the researcher gave further explanations using more accessible language until the participant had an understanding of the key elements of the study. Once consent was obtained, the WAIS-IV subtests were administered. Then, demographic information about the participant was obtained. The researcher read each item out loud and the participant replied verbally or typed the answer into a computer (when the participant replied verbally, the researcher typed the response into a computer). Then, data about the family network of the participant were collected using the FNM-ID, following the interview protocol described earlier. When the participant gave permission, this part of the data collection was audio recorded, to ensure all data were captured.

With the consent of participants, the researcher also planned an interview with the key support worker. Key

support workers were visited individually for 45–60 min. After informed consent was obtained, key support workers were questioned using the FNM-ID about their perceptions of the family network of the person with intellectual disability. Then, the ABCL and BPI-01 were computer-administrated. Proxy-report were used here instead of self-report to reduce the demand placed on participants with mild intellectual disability. Additional information about officially diagnosed psychiatric or developmental disorders according to file records were obtained. These records were checked by the key support workers and reported to the researcher. If necessary, the psychologist was contacted as well to provide additional confirmation. Key demographic information about the key support worker was collected as well.

The current study only included data from dyads of participants with mild intellectual disability and their key support workers. Data from nine participants with intellectual disability were excluded from the study because their IQ scores indicated that their cognitive abilities were above or below the mild intellectual disability range. In addition, data from the FNM-ID for one participant were excluded from the study; scores on all but one measures were found to be extreme outliers (3SDs or more above the mean). Therefore, 138 complete dyads of people with mild intellectual disability and key support workers were included in the current analysis.

### Data analysis

The family network data were entered into Excel. Subsequently, the Excel files were imported in Statnet a software package of R (R Core Team, 2011) to calculate the social network measures (Handcock et al., 2016). For both groups, people with intellectual disability and the key support workers, the social network measures were calculated separately. A selection of social network measures was made, based on the social capital theoretical framework (Sapin et al., 2016; Widmer, et al., 2010). First, the *size* of a network was calculated, so the number of family members within the network of the participant. In this study, both the total size of the family network and the size of the selection of “significant” members were used. Furthermore, the measures *in-degree* and *out-degree* were calculated. These represent how many relationships with received (in-degree) or given (out-degree) emotional support the person with intellectual disability had with other family members (Giesbers et al., 2019). We also calculated what proportion of the emotionally supportive relationships consisted of reciprocal support (*dyad reciprocity*; Hanneman & Riddle, 2005). Last, the *composition* of

the total family network was summarized in terms of the number per type of relationship which were listed during the interviews. For example, a participant listed two parents, one sibling and two professionals.

In the second phase of data analysis, the network measures were exported to SPSS and paired samples *t*-tests were conducted to examine differences in the characteristics of the family networks perceived by the participants with intellectual disability and their key support workers. A standardized mean difference effect size for paired designs, *d* was calculated using  $t [2(1-r)/n]^{1/2}$  (Dunlap et al., 1996). A conservative value of 0.80 was used to estimate *r* in that equation.

In the third phase of data analysis, dyad difference scores were calculated for four measures that revealed significant differences at the second step (i.e., size of the family network, size of the significant family members within the family network, and in- and out-degree). Because individual scores within a dyad are nested data involving two levels (individual – dyad) (Gonzalez & Griffin, 2012), difference scores were only used at the dyadic level of the analysis. Then, factors that may account for different perceptions between participants with intellectual disability and their key support workers on divergent network measures were examined using multiple regression analyses with the dyad’s difference score of the network measures as the dependent variable. The predictors for each regression model were the gender of the participant with intellectual disability, the living situation (residential or community), whether the person had at least one significant challenging behaviour, and the level of internalising and externalising behaviour. As it is not assumed that all dyads have the same mean, therefore, the mean score of the dyad on the dependent variable was included as a predictor, to correct for different dyad mean scores. This approach is called the residual change approach (Castro-Schilo & Grimm, 2018).

## Results

### Group differences in network perception

Paired samples *t*-tests were conducted to examine differences in the characteristics of the family networks perceived by the participants with mild intellectual disability and staff members. The results show significant differences on four out of five network measures.

**Network measures.** Participants with mild intellectual disability perceived both their total family networks,  $t(137) = -7.20$ ,  $p < .001$ , and their significant family networks,  $t(137) = -5.88$ ,  $p < .001$ , to be larger in size than did staff members (Table 1). Both results have small effect size.

**Table 1.** Mean numbers of the network measures for participants, *t*, *df*, *p*, *d*.

	Variable	Mean (SD)		<i>t</i>	<i>p</i>	<i>d</i>
		Individuals with intellectual disability	Staff members			
Full network	Size	9.98 (6.28)	6.28 (2.98)	-7.20	<.001	-0.388
Significant network	Size	7.18 (4.86)	4.96 (2.24)	-5.88	<.001	-0.317
Measures for individuals with intellectual disability	In-degree	2.34 (1.60)	1.59 (1.07)	-4.77	<.001	-0.257
	Out-degree	2.37 (3.54)	1.46 (1.83)	-2.80	<.006	-0.151
	Dyad-Reciprocity	0.29 (0.33)	0.33 (0.38)	-0.99	.322	-0.053

**Individual network measures.** Significant differences were found between the perceptions of participants with mild intellectual disability and key support workers in the amount of support. Participants with mild intellectual disability perceived that they had more relationships with family members in which they received support (i.e., in-degree), than staff members perceived,  $t(137) = -4.77, p < .001$ . This also applied to the perceived given support (i.e., out-degree) by the participant with mild intellectual disability,  $t(137) = -2.80, p = .006$ . All the significant differences for the individual network measures were associated with a small effect size. No significant group differences were found in the perceptions of the reciprocity of the family relationships of participants with mild intellectual disability,  $t(137) = 0.99, p = .322$ .

**Composition of family networks.** Differences in the perspectives of people with intellectual disability and key support workers on the total size of the family networks were analysed in more detail, by comparing the different types and numbers of listed family members. Table 2 presents the number of relationships per type of the relationship, as listed per group of participants. The results show that the significant difference in full network size may be attributed primarily to two types of relationships. Participants with mild intellectual disability listed more extended family,  $t(137) = -7.21, p =$

$<.001$ , and family members in-law,  $t(137) = -2.25, p = .026$ , than did key support workers, both associated with a small effect size. Both participant groups listed the same number of children in the family networks.

**Correlates of divergence**

To examine the differences in perceptions on the family network (Table 1) between people with mild intellectual disability and their key support workers, multiple regression analyses were conducted with possible predictors. Multiple regression models for total size of the family networks,  $F(6, 131) = 18.420, p < .001, R^2 = .46$ , the number of significant members in the family networks,  $F(6, 131) = 22.76, p < .001, R^2 = .51$ , the amount of in-degree,  $F(6, 131) = 5.54, p < .001, R^2 = .20$ , and out-degree  $F(6, 131) = 11.58, p < .001, R^2 = .35$  were statistically significant overall.

Examining the possible predictors in more detail, for all four network measures the dyad's mean score added statistically to the prediction (Table 3). For all network measures, a higher score on the dyadic mean score was associated with a larger difference in perspective on the network measure. This means, for example, that when the participant with mild intellectual disability listed more family members (total size) the chance that the key support worker did not list all the same family members increased. The differences between the perceptions of people with intellectual disability and key support workers are larger when family sizes increased. The same applied for the number of significant family members. When participants with mild intellectual disability thought they received (in-degree) support from more family members, it was more likely that key support workers listed fewer family members who were supportive. This was also the case for the perceived given support (out-degree).

Another notable result was that proportionally more predictors were significant for the differences in perspectives on the size of the significant family network. When participants with intellectual disability lived in a group home or apartment located in the community with full time staffing support, staff were more likely to agree who they considered as significant family

**Table 2.** Number of listed relationships in the family network, *t*, *df*, *p*, *d*.

Type of relationship	Mean (SD)		<i>t</i>	<i>p</i>	<i>d</i>
	Individuals with intellectual disability	Staff members			
Partner	0.13 (0.34)	0.11 (0.31)	-1.00	.319	-0.054
Parent	1.56 (0.60)	1.59 (0.58)	-1.07	.287	-0.058
Child	0.02 (0.15)	0.02 (0.15)	#	#	
Sibling	1.59 (1.24)	1.46 (1.16)	-1.57	.120	-0.085
Extended family	4.59 (5.27)	1.51 (1.67)	-7.21	<.001	-0.388
Family in-law	0.68 (1.10)	0.48 (0.95)	-2.25	.026	-0.121
Step family	0.48 (1.12)	0.39 (0.76)	-1.03	.305	-0.021
Foster family	0.36 (1.96)	0.25 (1.58)	-0.81	.421	-0.019
Friends	0.21 (0.64)	0.11 (0.41)	-1.66	.099	-0.089
Professionals	0.10 (0.54)	0.12 (0.59)	-0.36	.723	-0.019
Volunteer	0.08 (0.70)	0.06 (0.38)	-0.69	.493	-0.037
Other	0.18 (0.61)	0.17 (0.54)	-0.13	.897	-0.007

# The *t* and *p* value could not be computed because the standard error of the difference is 0.

**Table 3.** Summary of multiple regression analyses for variables predicting Dyad's difference scores.

Variable	Size total (n = 138)			Size significant (n = 138)			In-degree (n = 138)			Out-degree (n = 138)		
	B (SE)	t	p	B (SE)	t	p	B (SE)	t	p	B (SE)	t	p
Gender	-0.183 (0.815)	-0.224	.823	-0.043 (0.568)	-0.077	.939	-0.180 (0.305)	-0.592	.555	-0.095 (0.562)	-0.169	.866
Living setting	1.556 (1.103)	1.410	.161	1.608 (0.769)	2.091	.038	0.238 (0.412)	0.579	.564	0.867 (0.767)	1.129	.261
Challenging behaviour	-1.309 (0.953)	-1.374	.172	-0.591 (0.666)	-0.888	.376	-0.830 (0.356)	-2.333	.021	-0.121 (0.668)	-0.182	.856
Internalising behaviour	-0.085 (0.050)	-1.694	.093	-0.080 (0.035)	-2.279	.024	-0.025 (0.019)	-1.333	.185	0.015 (0.035)	0.431	.667
Externalising behaviour	0.029 (0.041)	0.704	.482	0.065 (0.029)	2.231	.027	0.027 (0.016)	1.723	.087	-0.021 (0.029)	-0.715	.476
Dyadic mean score	1.010 (0.100)	10.064	.000	0.980 (0.089)	11.059	.000	0.667 (0.148)	-4.503	.000	1.067 (0.135)	7.907	.000

Note. Constant = -3.27 (size total), 0.98 (size significant), -0.35 (in-degree), -1.08 (out-degree).

members, as compared to key support workers for people with intellectual disability living in more segregated, residential settings. When the individual with mild intellectual disability showed more externalising behaviour, the differences in the number of listed significant family members between people with mild intellectual disability and support key workers became larger. People with intellectual disability listed more significant family members than did support key workers. When the individual with mild intellectual disability showed more internalising behaviour, the differences in the number of listed significant family members by people with mild intellectual disability and staff members became smaller.

## Discussion

The results of the present study showed that people with mild intellectual disability perceived their family networks to be larger and to provide more support than their key support workers did. These findings suggest that there is some divergence in the perspectives of people with mild intellectual disability and key support workers about the characteristics and the support in family networks. There was notable disagreement about extended family members (e.g., aunts, uncles, nieces) and family in-law (typically partners of the brothers and sisters of the person with mild intellectual disability). People with intellectual disability and key support workers reported similar numbers of nuclear family (partner, parents, children, siblings). Extended and step family members may be less visible for key support workers, although people with intellectual disability consider them as significant. In fact, the current study explicitly allowed people with intellectual disability to define their significant family themselves. The fact that support workers did not know about (or potentially did not recognize) the importance of extended family suggests that they could be made more aware of extended family and consider relationships with extended family as a way to improve the social networks of people with intellectual disability.

An explanation for the differences in listed family members might be that people with mild intellectual disability typically meet members of those two family groups outside the context of the service provider (e.g., at the homes of their parents or of their brother or sister). We only included participants who lived apart from their family in long-term care. Therefore, support workers may not have an opportunity to meet all the family members of individuals they support, which may make it more difficult to provide a complete proxy-report using the FNM-ID. This suggestion is also

in line with the findings of Scott and Havercamp's (2018) research: staff members felt ill-equipped to rate the relationships of people with intellectual disability as they stated they were unaware of friendships/intimate relationships or had never seen the person interact with a friend/significant other. The results of this study seem to confirm this assumption, as participants who resided in a residential facility differed more from their support workers' perspectives regarding significant family members, than participants who lived in a community setting. Given that we examined other predictors of divergence in perspectives (including several service user factors), the setting effect might be related to the fact that key support workers who work in residential facilities have less insight into significant other family members, perhaps because families visit and contact their relative with intellectual disability less. There may also have been other characteristics of the people with intellectual disability associated with this setting difference that were not measured in the current study. All of these possibilities could be explored in future research.

Another finding was that the participants with mild intellectual disability estimated that they were more emotionally supportive to family members and received more emotional support from their family members than their support key workers estimated. This might indicate that the validity or accuracy of the key support workers when reporting on the emotional support in family networks of people with mild intellectual disability is questionable. A potential other explanation for these different perspectives might be that a positive illusory bias inflated the self-perceptions of people with intellectual disability. Earlier research showed that people with intellectual disability may be at risk of greater biases in perceptions of social relationships because other individuals' feelings are often misunderstood (Lavin & Doka, 1999). This is in line with Lunsy and Benson's (2001) research, which found that people with mild intellectual disability had difficulties with interpreting social situations as well as the emotions of others. Based on video vignettes, 50 people with intellectual disability were asked to interpret different social situations. The results suggested that interpretations of social support were based in part on prior conceptions about social support. For example, people who perceived their own support as low and also reported high levels of loneliness, rated the video vignettes as less supportive than people who viewed their own situations more positively. In addition, people with intellectual disability rated the video vignettes more positively than did the 40 support members who also participated in the study. Another hypothesis for this putative self-

inflated perception of people with mild intellectual disability might be that it is difficult to admit that their social networks are small, or they might feel lonely. It may serve a self-protective function; helping to maintain a positive self-image. Such a function has been observed in children with externalizing behaviour problems, who tend to inflate their status in, and the quality of, social relationships with both peers and family members (Barry, 2011). Nonetheless, social networks can be conceptualized as cognitive structures, based on the assumption that "perceptions are real in their consequences, even if they do not map one-to-one onto observed behaviours" (Krackhardt, 1987, p. 128).

The difference in the perceived number of significant family members, between people with mild intellectual disability and their key support workers, was found to be related to the internalising and externalising behaviour of the person with mild intellectual disability. That is, the difference in perspectives became larger when the person with mild intellectual disability showed higher levels of externalising behaviour. In contrast, the differences in perspectives reduced when the person with mild intellectual disability showed higher levels of internalising behaviour. An explanation for these differences might be that support staff develop different attitudes towards people with externalising versus internalising behaviour (Van Dam et al., 2011). Previous research has shown that support staff had a warmer and more supportive attitude towards people with internalizing problems, and a more structured and controlling attitude towards adolescents with externalizing problems (Van Dam et al., 2011). A supportive attitude towards people with internalising behaviour might lead to a better understanding of individuals' needs and wishes, and a greater awareness of their supportive social relationships. When staff are more focussed on controlling the (externalising) behaviour of the person with intellectual disability, they might have less insight into the nature of their social support.

It may also be the case that people with a mild intellectual disability who display externalising behaviour have fewer mutually supportive relationship than their peers. Limited emotional support might be a result as well as a cause of externalising behaviour (Schuiringa et al., 2015). However, this pattern was not found in our study. Moreover, challenging behaviour predicted more agreement about the emotional support received from family members. The higher level of agreement could be due to the fact that the measure of challenging behaviour includes self-injurious behaviour and stereotyped behaviour (cf. externalising behaviour). In contrast to aggression, self-injurious and stereotyped behaviour pose less threat

to staff and evoke more sympathy and understanding (Noone et al., 2006).

Some limitations with the current study need to be discussed as they relate to the generalizability of the current findings. First, only 42.4% ( $n = 150$ ) of the randomly selected people who met the inclusion criteria agreed to take part in the study, so there is a risk of non-response bias. Unfortunately, no data were available for the non-respondents, and so biases in the sample selection cannot be quantified. Second, all participants lived in a facility managed by a service provider where they received regular staff support (from a few visits each week to 24/7 support). Future research should address the perceptions of individuals with mild intellectual disability who live independently at their own home, with and without support. Furthermore, a distinction can be made between emotional and instrumental support. This study focused on emotional support, as it has been found to be a stronger predictor for physical and mental health-related outcomes (Berkman, 1995; Thoits, 1995). It would be useful in future research to also look at perspectives on instrumental support in family networks.

There are several findings from the current study that add to our understanding of how people with mild intellectual disability perceive the emotional support in their family networks compared to the perceptions of their key support workers. In particular, we contributed to literature suggesting that the perspectives of staff and people with intellectual disability may differ but importantly we examined factors that might be associated with diverging perspectives. Support workers could become more aware that the living setting or the behaviour someone displays might bias their perspective on someone's family network and perceived emotional support. Divergence in perspectives might be detrimental because better informed support workers might be better able to support individuals with intellectual disability to maintain links between them and their family members. Second, support staff should be aware that people with intellectual disability might rate their social support differently than people without intellectual disability, due to their "support schemas" based on their previous experiences (Lunsky & Benson, 2001). Last, if key support workers are consulted as proxies for the FNM-ID measure specifically, the data should be interpreted with caution especially when key support workers have known the individual for a limited amount of time and/or see that person in one context only. Moreover, when self-report is not feasible, it may be useful to gather proxy reports from more than one source if possible, to obtain a fuller picture of the person's life and experiences.

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No potential conflict of interest was reported by the author(s).

## ORCID

Tess Tournier  <http://orcid.org/0000-0002-8726-8100>

Alexander H. C. Hendriks  <http://orcid.org/0000-0002-8303-8527>

Andrew Jahoda  <http://orcid.org/0000-0002-3985-6098>

Richard P. Hastings  <http://orcid.org/0000-0002-0495-8270>

Sanne A. H. Giesbers  <http://orcid.org/0000-0001-8358-5806>

Petri J. C. M. Embregts  <http://orcid.org/0000-0003-3567-1528>

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