

## Family-based social capital of emerging adults with and without mild intellectual disability

S. A. H. Giesbers,<sup>1,2</sup>  A. H. C. Hendriks,<sup>3</sup> R. P. Hastings,<sup>4,5</sup>  A. Jahoda,<sup>6</sup> T. Tournier<sup>1,7</sup>   
& P. J. C. M. Embregts<sup>1</sup> 

<sup>1</sup> *Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, the Netherlands*

<sup>2</sup> *Dichterbij Innovation and Science, Gennep, the Netherlands*

<sup>3</sup> *School of Pedagogical and Educational Science, Faculty of Social Sciences, Radboud University Nijmegen, Nijmegen, the Netherlands*

<sup>4</sup> *Centre for Educational Development, Appraisal and Research, University of Warwick, Coventry, UK*

<sup>5</sup> *Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, School of Clinical Sciences at Monash Health, Monash University, Clayton, Australia*

<sup>6</sup> *Psychological Medicine, University of Glasgow, Glasgow, UK*

<sup>7</sup> *ASVZ, Shiedrecht, the Netherlands*

### Abstract

**Background** Family is recognised as an important context for the self-development of young adults in emerging adulthood, although very little research has addressed the perspective of young people with intellectual disability about their families by using self-report. This study examined how emerging adults with mild intellectual disability define their family support networks, compared with definitions of students without intellectual disability, within a social capital theoretical framework.

**Methods** Fifty-three participants with mild intellectual disability and 53 students without intellectual disability were interviewed individually using the Family Network Method – Intellectual Disability (FNM-ID). Data from the FNM-ID relate to key social network measures on how individuals define their family groups, and how they perceive existing supportive relationships within their families.

Participants with mild intellectual disability and students were compared on the FNM-ID social network measures.

**Results** Participants with mild intellectual disability reported fewer family members who they considered significant to them than students without intellectual disability. They were less likely to include peers (i.e. friends and partners) and siblings in their significant family networks, had fewer relationships with family members in which they received or gave support, had fewer reciprocal support relationships and had a less central position in their family network.

**Discussion** The family-based social capital of emerging adults with mild intellectual disability differed from that of students without intellectual disability. They may remain more dependent on their natural family for emotional support as their supportive networks have not necessarily made the transition to networks with emotionally close peer relationships.

**Keywords** emerging adults, emotional support, family relationships, family support, social capital, social networks

Correspondence: Dr. Sanne A. H. Giesbers, Tilburg University, P. O. Box 90153, 5000 LE Tilburg, the Netherlands (e-mail: s.a.h.giesbers@tilburguniversity.edu).

## Background

The Convention on the Rights of Persons with Disabilities (United Nations 2006) aims for 'full and effective participation and inclusion in society' (Art. 3) of people with disabilities. More specifically, the Convention on the Rights of Persons with Disabilities recognises the importance of individual autonomy and independence of people with disabilities, including the freedom to make their own decisions.

The period in life when individuals typically focus on their self-development and development of individual autonomy is known as emerging adulthood (Arnett 2000). Emerging adulthood is conceptualised as a relatively new and distinct period in the life course of young individuals in the transition to adulthood (between 18 and 25 years of age). It is characterised by increased autonomy and identity exploration of work, love and worldviews as well as gradually becoming self-sufficient (Arnett 2000); that is, becoming a person who accepts responsibility for oneself and is able to make independent decisions (Arnett 1998). From a relational autonomy perspective, self-development takes place within the social context in which individuals are embedded, in relationships with other people (Mackenzie and Stoljar 2000; Walter and Friedman Ross 2014).

Family is an important context for the self-development of individuals (Kagitcibasi 2005). During emerging adulthood, most individuals' supportive networks transition from family-centred networks to networks that are more centred around peers, and the function of family relationships may change significantly (Fraley and Davis 1997; Aquilino 2006; Tanner 2006; Conger and Little 2010). In particular, parents and siblings become more peripheral, whereas romantic partners and friends have a more central place in daily life, with increased intimacy, emotional depth and communication about important personal matters (Collins and Van Dulmen 2006). Ferguson and Ferguson (1996) refer to these changing family relationships as the familial adulthood, as differentiated from the personal and cultural adulthood. The familial meaning of adulthood involves gradually changing relationships between a person and his or her parents and family, resulting in increased independence and autonomy for the person and less involvement and responsibilities for parents.

Family clearly also plays a significant role in the lives of people with intellectual disability (Van Asselt-Goverts *et al.* 2013; Sanderson *et al.* 2017). Research suggests that social networks of adults with mild intellectual disability mainly consist of family members and include relatively few friends (Rosen and Burchard 1990; Lippold and Burns 2009; Van Asselt-Goverts *et al.* 2013). Also, the inclusion of romantic partners is rare (Widmer *et al.* 2013). While people with intellectual disability identify behaviours and actions that foster or undermine friendships (Callus 2017), their friendship descriptions differ from those of their typically developing peers (Matheson *et al.* 2007). The friendships of young people with intellectual disability are also found to be characterised by lower levels of warmth, closeness and reciprocity (Tipton *et al.* 2013). Parents remain the main providers of informal support for people with intellectual disability, not only for practical (Sanderson *et al.* 2017) but also emotional support (Giesbers *et al.* 2020). As such, for emerging adults with intellectual disability, it may be difficult to attain adult roles within their family (Walmsley 1996; Mill *et al.* 2009).

Despite the recognition of the significance of the family for people with intellectual disability, very little research has addressed the perspective of people with intellectual disability about their families by using self-report. Gaining insight into the family support experiences from people themselves is important, as they are the experts and authorities on their lives, feelings, and experiences (McDonald *et al.* 2013). Furthermore, in general, family research has focused on a small number of family dyads (i.e. marital couples, parents and biological children or siblings), in which it is predefined what constitutes the family (Widmer 2016). Dyadic relationships (between a person and his/her network members) cannot be seen as isolated from the broader social context. As such, the research literature requires a theoretical foundation to examine more broadly how people define their family group and how the relationships within their family group are intertwined. It is important to examine how people with intellectual disability themselves define their significant family group in emerging adulthood, compared with people without disabilities.

A potentially relevant theoretical perspective is that family could be considered as a significant

source of social capital (Bourdieu 1986; Furstenberg and Kaplan 2004; Widmer 2016). Social capital is about the mutual exchange of supports or resources between individuals (Bullen and Onyx 1999). From a social capital perspective, positive and supportive family relationships that may go beyond the nuclear family (i.e. family-based social capital) are expected to have a variety of positive outcomes for the individual, such as promoting physical and mental health (Kawachi *et al.* 1999; Kawachi and Berkman 2001; McPherson *et al.* 2014; Riumallo-Herl *et al.* 2014). Widmer *et al.* (2008) examined the views of individuals with mild intellectual disability about their family from a social capital theoretical perspective. Widmer *et al.*'s findings suggest that family-based social capital is influenced by the presence of an intellectual disability. This held true for both types of social capital that are related to the family: bonding and bridging social capital (Coleman 1988; Burt 1995). Bonding social capital refers to dense networks in which all or most individuals are interconnected (Coleman 1988). Dense networks enhance expectations, obligations and trust among their members and support becomes collective. The second kind of social capital is bridging social capital, referring to the absence of relationships in a network that create relational holes in its structure (Burt 1995). As a result, some individuals (i.e. brokers) are more central in a network and mediate the flow of resources among network members, and therefore influence others, leading to feelings of autonomy, competence and control (Burt 1995). Widmer *et al.* found that adults with mild intellectual disability had less dense networks than people without disability (i.e. bonding social capital). They also had a less central position in their network (i.e. bridging social capital), meaning that they may experience less autonomy, competence or control within their families. This finding was even stronger for people with comorbid psychiatric disorders. However, this previous work relied on a small purposive sample and did not include specific measures of reciprocity, which is one of the main characteristics of social capital. Also, previous research has not used network methodology that has been adapted for people with intellectual disability.

We could find no studies from a social capital theoretical perspective with a specific focus on the

significant networks of individuals with mild intellectual disability in the important transition period of emerging adulthood, nor on reciprocity as a characteristic of mutual exchange of these family networks of individuals with mild intellectual disability. In addition, relatively few studies have used comparison groups of people without intellectual disability with which to evaluate the impact of disability on young people's experiences of family based social capital. Therefore, the current study focuses on the way a group of randomly sampled emerging adults with mild intellectual disability who live apart from family define their significant family group, and how they describe their family networks in terms of emotional support compared with students of the same sex and age who live apart from family, using family network methodology that has been adapted for people with mild intellectual disability within the theoretical framework of social capital (Giesbers *et al.* 2019). More specifically, our main research question was how are the self-reported family network characteristics and family support experiences (i.e. key social network measures) of people with a mild intellectual disability different or similar to those of students without intellectual disability?

## Methods

### Participants

Participants were 53 individuals with mild intellectual disability (IQ 50–70) and 53 students without intellectual disability in post-secondary education. Participants with mild intellectual disability had a mean age of 22.0 years ( $SD = 2.38$ , range 18–25 years). Thirty-four (64.2%) were male participants, and all but three (94.3%) had a Dutch cultural background. All participants with a mild intellectual disability lived apart from their family in housing with support from a service provider; a majority of 41 participants with disability (77.4%) lived in community-based settings [i.e. group homes or (clustered) apartments located in the community] and 12 lived in residential, more segregated, facilities (i.e. sites where larger numbers of people with intellectual disability live together). Of the participants with mild intellectual disability, 32 (60.4%) lived together with other service users, 19

(35.8%) lived individually, 1 lived together with a partner and 1 lived together with a brother (both 1.9%).

Students had a mean age of 21.6 ( $SD = 2.09$ , range 18–25 years) and 32 (60.4%) were male students. All students had moved out the family home: A majority of 33 students lived together with (a) roommate(s) (62.3%), 13 lived together with a partner (24.5%), 5 lived individually (9.4%), 1 lived together with a friend and 1 lived together with a brother (both 1.9%). Forty-seven students (88.7%) had a Dutch cultural backgrounds, and students were studying on three levels: vocational training ( $n = 21$ , 39.6%), university of applied sciences ( $n = 20$ , 37.7%) and university ( $n = 12$ , 22.6%). Vocational training focuses on the necessary knowledge and skills for a chosen occupation. Universities of applied sciences have a professional orientation and provide theoretical and practical training, whereas universities have an academic orientation and focus on training in academic disciplines.

#### *Family networks*

Participants were questioned about their family networks using the Family Network Method – Intellectual Disability (FNM-ID; Giesbers *et al.* 2019). To ensure that the data collected with participants with mild intellectual disability and students would be comparable, both groups were interviewed using the FNM-ID. The FNM-ID maps the family network and measures the significant family members of the participant and the family members who provide emotional support. It contains four steps. First, participants are asked to map their family network. Participants are instructed to use their own definition of the term ‘family’ and to define who they consider to be their family. As such, participants may use not only broader but also narrower definitions than more traditional definitions of the concept of family. They may, for example, include friends and can leave out biological family members (such as siblings) if they do not ‘feel’ like family. To avoid priming participants’ answers, this instruction does not contain examples of relationship types that could be included in the family network. The names of the listed family members are written down on separate cards, including a card with the name of the participant. Second, participants are

instructed to define their significant (‘significant’ is left to the participant to define for themselves) family members from all members listed at step one by asking them ‘Which members of your family are significant to you?’ In a third step, questions about the provision of emotional support are asked. Participants are not only asked about their own relationships with their family members (in terms of emotional support) but are also asked to consider the relationships that exist between all family members. That is, after participants are asked about which family members they feel supported by when they ‘feel out of sorts’, the same question is asked in relation to all other members of family network. For example, participants are asked: ‘when your mother is feeling out of sorts, who is there for her?’ Last, participants are asked to assess their own significance from the perspective of their family members. Additionally, key demographic data about all listed family members (e.g. sex, age and place of residence) are collected.

#### *Cognitive ability*

The subtests ‘Vocabulary’ and ‘Matrix Reasoning’ of the WAIS-IV-NL were administered to participants with mild intellectual disability only (Wechsler 2012). An estimation of their IQ scores was made (see *Procedure*) to check whether they met the inclusion criterion of having an IQ between 50 and 70. This estimation was made based on subtest standard scores. The subtests ‘Vocabulary’ and ‘Matrix Reasoning’ correspond with the two-subtest form of the WASI-II (Wechsler 2011). The WASI-II is an abbreviated version of the WAIS-IV and serves as a screening tool and brief measure of intelligence. As no Dutch version of the WASI-II is available, the two corresponding WAIS-IV-NL subtests were used in this study. This additional check on mild intellectual disability was included in the study, as file scores were often outdated, obtained with different IQ measurements or missing.

#### *Procedure*

Ethical approval was obtained from the Ethical Review Board of Tilburg University (EC-2015.46). The 53 participants with mild intellectual disability were part of a larger sample of 150 individuals with mild intellectual disability aged 18–40 years (Giesbers *et al.* 2020). For the current study, they were selected

from the larger sample based on the criterion that they were aged between 18 and 25 years as a match with the student sample in the emerging adulthood period. The 150 participants with mild intellectual disability of the original sample were randomly selected from five organisations providing services to people with intellectual disability. A stratified sampling procedure was used; of each participating service provider, 10% of service users who met inclusion criteria participated in the study. The inclusion criteria were (1) a mild intellectual disability (IQ 50–70) according to file records, (2) aged between 18 and 40 years and (3) receiving professional support from the service provider at least once a week for a minimum of 6 months. Participants with mild intellectual disability were always approached in consultation with support staff. First, the aims and procedure of the study were explained to staff on the telephone. Afterwards, an information letter was sent to staff, and they were asked to discuss the information letter with the selected service users. This letter included information about the aims and content of the study and the confidentiality of the data.

Staff of 354 individuals who met inclusion criteria was asked to invite the selected service users to participate in the study, of which 150 participated (42.4%). With those service users who were willing to participate, an appointment was scheduled at their home or, if preferred, another location within the service provider's facilities. Data were collected by the first author, the fifth author and a research assistant. Participants were visited individually by the researcher for the duration of approximately 45 to 60 min per visit. Each visit started with small talk to put the participant at ease.

A standard consent procedure was followed to ensure that participants with mild intellectual disability could provide their informed consent (Arscott *et al.* 1998). After explaining the research project to participants (both verbally and with written information), the researcher determined whether they could recall (1) the general content of the questions, (2) how many times they would be interviewed, (3) possible positive and negative aspects regarding participation and (4) that they could withdraw from the study at any time (without explanation). If needed, the researcher explained these four points in simpler or alternative words until the participant had an understanding of the key aspects of the study.

After participants gave their informed consent, WAIS-IV-NL subtests were administered, following the prescribed procedure. Next, demographic data were collected. During the last and main part of the visit, participants were questioned about their family network using the FNM-ID. After participation, standard scores for the WAIS-IV-NL subtests were computed. A participant was not considered to have mild intellectual disability when the standard scores on both subtests were outside the mild intellectual disability range (taking the reported standard errors into account). As a result, data from 11 participants were excluded (including seven participants aged 18–25 years) from the dataset.

Inclusion criteria for students were that they (1) had moved out the family home, (2) were aged between 18 and 25 years and (3) were attending post-secondary education (i.e. vocational training, university of applied sciences or university). First, students from the three levels of post-secondary education were included proportionally, based on the student numbers per level of education that exist in Dutch post-secondary education (Centraal Bureau voor de Statistiek 2017). Also, it was ensured that students would be comparable with the subsample of participants with mild intellectual disability in terms of age and sex. Therefore, age was categorised into two categories (18–21 and 22–25 years), after which the existing proportions of male and female participants within both age categories were calculated for the subsample of participants with mild intellectual disability. Statistical testing showed that there were no significant differences between the sample of students and participants with mild intellectual disability in terms of age in years,  $t(104) = -0.74$ ,  $p = .462$  and sex,  $\chi^2(1) = 0.16$ ,  $p = .689$ .

The 53 students were from nine post-secondary educational institutions located in seven different cities throughout the Netherlands. They were recruited by a contact person from their educational institution or face to face by the researcher. When recruited by a contact person, students who were willing to participate gave their permission to provide the researchers with their contact details, after which the researcher contacted them by telephone to explain the study and to schedule an appointment for a face to face interview. Also, an email was sent to students to confirm the appointment and to send them an



information letter. Interviews were held at the educational institution or at the homes of participants. When students were recruited face to face at their educational institution, the interview took place at the same time as recruitment. The researcher first explained the aim, content and confidentiality of the study, after which participants were given the opportunity to read the information letter and ask questions concerning participation.

At the start of each interview, the informed consent form was signed, after which participants were questioned about their family network using the FNM-ID. Also, demographic information (e.g. sex, age and level of education) was collected for each participant.

### Data analysis

Family network data were entered into Excel and analysed using UCINET (Version 6.623; Borgatti *et al.* 2002). Several social network measures, of interest within a social capital theoretical perspective, were computed (Giesbers *et al.* 2019) (see Table 1). Also, the type of family relationship was measured for the significant and supportive/supported family members. Next, UCINET output was imported into SPSS for the group comparisons (carried out using independent sample *t*-tests and chi-square tests).

## Results

### Network measures

Independent samples *t*-tests were conducted to examine differences in the characteristics of the family networks of participants with mild intellectual disability and students (see Table 2).

With regard to the network measures (i.e. measures concerning the network as a whole), family networks of participants with mild intellectual disability and students were found to differ significantly in terms of size, with a medium to large effect size (Cohen 1988). That is, participants with mild intellectual disability had significantly smaller family networks,  $t(104) = -3.44, p = .001$ , and listed fewer significant family members,  $t(86.34) = -3.51, p = .001$ . Despite small to moderate effect sizes, differences in network density,  $t(91.69) = 1.65, p = .101$ , and dyad reciprocity were not statistically significant,  $t(97.46) = -1.92, p = .057$ .

### Individual family network measures for participants

The two subsamples differed on all individual network measures, with medium sized effects (Table 2). Participants with mild intellectual disability had fewer relationships with family members in which support was received (i.e. in degree),

**Table 1** Overview of the computed social network measures

Network measures – full network	Size	Number of listed family members
Network measures	–Size	Number of significant family members
significant network	Density	The number of relationships between network members compared with the maximum possible numbers of relationships that could theoretically exist between all family members. For example, in highly dense networks, (nearly) all members are interconnected.
	Dyad Reciprocity – all relationships	The number of dyads in the network with reciprocal relationships, divided by the total number of adjacent dyads in the network. For example, in networks with a high reciprocity, (nearly) all support relationships are mutual
Individual family network measures for participants	Indegree	Number of relationships in which the participant receives support
	Outdegree	Number of relationships in which the participant provides support
	Betweenness centrality	The proportion of relationships for which the participant was an intermediary. It quantifies the number of times a network member acts as a bridge along the shortest path between two other network members.
	Dyad reciprocity – only relationships of participant	–The number of dyads (in which the participant is an actor) with reciprocal relationships, divided by the total number of adjacent dyads (in which the participant is an actor)

**Table 2** Mean numbers of the network measures for participants, *t*, *p* and Cohen's *d*

Variable	Mean (SD)		<i>t</i>	<i>p</i>	Cohen's <i>d</i>
	Individuals with MID ( <i>n</i> = 53)	Students ( <i>n</i> = 53)			
Full network	Size	9.85(5.54)	14.11(7.12)	-3.44.001	.67
Significant network	Size	6.15(4.37)	10.17(7.11)	-3.51.001	.68
	Density	0.37(0.24)	0.31(0.16)	1.65.101	-.29
Measures for participants	Dyad reciprocity – all relationships	0.42(0.30)	0.52(0.23)	-1.92.057	.37
	Indegree	2.47(1.61)	4.02(4.18)	-2.52.014	.49
	Outdegree	3.34(3.42)	5.53(4.32)	-2.89.005	.56
	Dyad reciprocity – relationships of participant only	0.32(0.30)	0.47(0.29)	-2.50.014	.51
	Betweenness centrality	10.94(24.49)	39.42(75.72)	-2.61.011	.51

$t(67.17) = -2.52, p = .014$ , or given (i.e. out degree),  $t(104) = -2.89, p = .005$ , than students had. Also, participants with mild intellectual disability experienced their relationships with family members as less reciprocal than students did,  $t(104) = -2.50, p = .014$ . Finally, participants with mild intellectual disability perceived themselves to be in a less central position in their family network,  $t(62.76) = -2.61, p = .011$ .

### Composition of family networks

Chi-square tests or, in case of low cell frequency, Fisher's exact tests were conducted to assess differences in the composition of the significant family network. Table 3 shows that, compared with students, a significantly smaller proportion of participants with mild intellectual disability included a partner,  $\chi^2(1) = 5.52, p = .019$ , sibling,  $\chi^2(1) = 7.19, p = .007$  or

**Table 3** Types of relationship in the significant Family Network,  $\chi^2$ , *p* and phi

Type of relationship	<i>n</i> (%)		$\chi^2$	<i>p</i>	phi
	Individuals with MID ( <i>n</i> = 53)	Students ( <i>n</i> = 53)			
Partner	10(18.9)	21(39.6)	5.52	.019	.23
Parent	46(86.8)	46(86.8)	0.00	1.000	.00
Child	1(1.9)	0(0.0)	--	1.000 <sup>a</sup>	-.10
Sibling	37(69.8)	48(90.5)	7.19	.007	.26
Extended family	33(62.3)	40(75.5)	2.16	.142	.14
Family in-law	11(20.8)	7(13.2)	1.07	.301	-.10
Step family	11(20.8)	6(11.3)	1.75	.186	-.13
Foster family	5(9.4)	2(3.8)	--	.437 <sup>a</sup>	-.11
Friends	4(7.5)	22(41.5)	16.51	< .001	.40
Others	7(13.2)	5(9.4)	0.38	.540	-.06

<sup>a</sup>Fisher's exact test

friend,  $\chi^2(1) = 16.51, p < .001$ , in their significant network. These differences were small to medium effect sizes for partners and siblings and medium to large for friends (Murphy and Myers 1998).

Group differences in the composition of support relationships were also assessed. Table 4 shows the proportion of participants with mild intellectual disability and students that reported at least one supportive (i.e. in degree) or supported (i.e. out degree) relationship within each family relationship category. Participants with mild intellectual disability were less likely to report receiving support from partners,  $\chi^2(1) = 6.99, p < .008$ , and friends,  $\chi^2(1) = 18.90, p < .001$ . These differences were associated with medium-sized effects for partners and medium to large-sized effects for friends (Murphy and Myers 1998). Participants with intellectual disability were also less likely to report giving support to partners,  $\chi^2(1) = 5.52, p < .019$ , friends,  $\chi^2(1) = 15.73, p < .001$ , parents,  $\chi^2(1) = 5.53, p < .019$  and siblings,  $\chi^2(1) = 10.10, p = .001$ . Effects for

partners and parents were small to medium, effects for siblings were medium and effects for friends were medium to large in terms of size.

## Discussion

This study examined the views of emerging adults with mild intellectual disability about their family support networks and compared these views with those of students without intellectual disability of the same sex and age, within a social capital theoretical framework.

We found that the family-based social capital of emerging adults with mild intellectual disability differed from that of students without intellectual disability. First, family networks of participants with mild intellectual disability consisted of fewer members, and in line with previous research (Widmer *et al.* 2008), participants with mild intellectual disability reported fewer 'significant' family members than students without intellectual disability. More

**Table 4** Type of relationship in terms of received support (indegree) and given support (outdegree),  $\chi^2$ ,  $p$  and phi

Measure	Type of relationship	n (%)		$\chi^2$	p	phi
		Individuals with MID	Students			
		(n = 53)	(n = 53)			
Indegree	Partner	8(15.1)	20(37.7)	6.99	.008	.26
	Parent	39(73.6)	34(64.2)	1.10	.294	-.10
	Child	0(0.0)	0(0.0)	--	--	--
	Sibling	16(30.2)	24(45.3)	2.57	.109	.16
	Extended family	15(28.3)	9(17.0)	1.94	.164	-.14
	Family in-law	5(9.4)	3(5.7)	--	.716 <sup>a</sup>	-.07
	Stepfamily	4(7.5)	2(3.8)	--	.678 <sup>a</sup>	-.08
	Foster family	4(7.5)	1(1.9)	--	.363 <sup>a</sup>	-.13
	Friends	3(5.7)	22(41.5)	18.90	< .001	.42
	Others	4(7.5)	2(3.8)	--	.678	-.08
Outdegree	Partner	10(18.9)	21(39.6)	5.52	.019	.23
	Parent	24(45.3)	36(67.9)	5.53	.019	.23
	Child	1(1.9)	0(0.0)	--	1.000 <sup>a</sup>	-.10
	Sibling	24(45.3)	40(75.5)	10.10	.001	.31
	Extended family	21(39.6)	23(43.4)	0.16	.693	.04
	Family in-law	6(11.3)	5(9.4)	0.10	.750	-.03
	Stepfamily	2(3.8)	3(5.7)	--	1.000 <sup>a</sup>	.04
	Foster family	3(5.7)	0(0.0)	--	.234	-.17
	Friends	5(9.4)	23(43.4)	15.73	<.001	.39
	Others	5(9.4)	4(7.5)	--	.000 <sup>a</sup>	-.03

<sup>a</sup>Fisher's exact test



specifically, they significantly were less likely to include peers (i.e. friends and romantic partners) and siblings as significant family members.

Furthermore, participants with mild intellectual disability had significantly fewer relationships with family members in which they received support (associated with a medium effect size). This is an important finding, given that they may be particularly dependent on the support of significant others (Thompson *et al.* 2009). In addition, in recent times when there have been cuts in services, individuals with intellectual disability have become increasingly reliant on their informal supportive networks for their social capital (Simplican *et al.* 2015). However, the current findings show that emerging adults with mild intellectual disability felt they had less access to supportive resources from the family, potentially resulting in a more vulnerable position.

Moreover, participants with mild intellectual disability had significantly fewer relationships where they felt that they provided support to family members (a medium effect size difference). Participants with mild intellectual disability were less likely to report relationships with peers and nuclear family members (i.e. parents and siblings) that involved them supporting the family member. Also, their relationships with family members were less likely to be reciprocal. Reciprocity is one of the key features of social capital (Bullen and Onyx 1999), and research has shown that opportunities to provide support for others and to have reciprocal relationships have been associated with feelings of self-worth and better mental and physical health (Liang *et al.* 2001; Forrester-Jones and Barnes 2008; Thomas 2010). People with intellectual disability have also stressed the importance of reciprocity to make them feel useful and to challenge feelings of dependence (Milner and Kelly 2009). However, in line with the findings of the current study, they have also indicated that they often experience that their relationships are not based on reciprocity (Milner and Kelly 2009). To contribute to feelings of self-worth and to challenge feelings of dependence, staff could focus on the support that people with intellectual disability may be able to offer to their significant others. In addition, reciprocity helps to ensure continuing relationships and exchanges (Bullen and Onyx 1999).

The current findings suggests that, contrary to the pattern that is found in the general population

(Fraley and Davis 1997; Aquilino 2006; Tanner 2006; Conger and Little 2010), the supportive networks of emerging adults with mild intellectual disability have not necessarily made the transition to networks that are more centred around peers, with emotionally close peer relationships. Compared with students without disability, the differences in the inclusion of significant and/or supportive/supported friends were associated with large sized effects. This situation might be dissatisfying for young people with mild intellectual disability, as other research has shown their wish for closer relationships with peers (Healy *et al.* 2009; Rushbrooke *et al.* 2014; Friedman and Rizzolo 2018; Giesbers *et al.* 2019). In particular, the lack of a romantic partner can make some individuals feel unable to achieve the ordinary future they want, including settling down and having a family of their own (Rushbrooke *et al.* 2014; Neuman and Reiter 2017). Thus, our findings suggest that emerging adults with mild intellectual disability remain more dependent on their natural family for emotional support, while they themselves were less likely to have a supportive role in their nuclear family (i.e. for parents and siblings), and support was less reciprocal compared with the students without intellectual disability. This finding is important because positive effects of reciprocity on caregiver wellbeing have been shown in several studies (Carruth *et al.* 1997; Heller *et al.* 1997; Reid *et al.* 2005). For example, Heller *et al.* (1997) found that when parents experienced greater support from an adult child with intellectual disability, they experienced less burden and higher levels of caregiving satisfaction.

Contrary to Widmer *et al.* (2008) study, participants with a mild intellectual disability in the present study did not perceive their significant networks to be less dense (and this was associated only with a small effect size), but they did perceive themselves to be in a less central position in their family network. That is, compared with students without intellectual disability, participants with intellectual disability fulfilled less of a 'broker' role in their network. These findings mean that participants with mild intellectual disability experienced similar levels of bonding social capital compared with students without intellectual disability, while experiencing a lower level of bridging social capital. It

might be possible that the presence of an intellectual disability hinders the development of social relationships that require reciprocity (e.g. friends and more extended family) (Gouldner 1960; Cornwell 2009). It is these types of relationships in particular that could give rise to bridging social capital (Aeby *et al.* 2014). They enable the individual to fulfil a 'broker' function in their network in which they could mediate the flow of resources among network members, entailing feelings of autonomy and control (Burt 1995). Because of the lack of these reciprocal relationships, the presence of an intellectual disability may lead to more restricted social networks with greater interconnectedness among its members (Cornwell 2009). Consistent with this prediction, in the current study, participants with mild intellectual disability did perceive their significant networks as smaller, but they did not perceive their network as more interconnected. Decreased levels of bridging social capital may hinder the autonomy of emerging adults with mild intellectual disability within their families (Woolcock 1998). It is important for staff and service providers to recognise this finding when encouraging informal support.

The current findings should be considered within the limitations of the study. First, there is a risk of non-response bias. Only 42.4% of the randomly selected individuals with mild intellectual disability (18–40 years) participated in the overarching research, and this may also have negatively affected the representativeness of the sub-sample of participants with mild intellectual disability aged 18–25 years. Furthermore, the study concerned a specific group of participants with mild intellectual disability; they all lived apart from family, with frequent support from paid staff. Future research should address emerging adults with mild intellectual disability living with their natural family or in other types of support arrangements. Also, future studies might also include people with a borderline level of functioning, to examine possible differences in the family-based social capital of people with mild intellectual disability and people with a borderline level of functioning. In the Netherlands, they are often approached as a homogenous group in policy and practice. However, even though they may experience (partly) overlapping support needs, significant differences may also exist between these groups, in terms of their vulnerability and the complexity of their support needs (Nouwens

*et al.* 2017). As such, it might be important to assess how their family structures may be functionally similar or different.

Second, all participants without mild intellectual disability were students of post-secondary education, making the comparison group a selected group of emerging adults. Even though three educational levels were (proportionally) represented in the current study, it would be important for future studies to include a randomly selected sample of adults that may, for example, also involve emerging adults who do not or did not follow (post-secondary) education, or have already made the transition to work.

In addition, participants with mild intellectual disability and students were compared only on age and sex. We did not collect data on how these two groups compared on other variables. As such, we were unable to examine whether differences in family-based social capital could be attributed to the presence of an intellectual disability or whether other factors accounted for these differences. For example, it would be important for future research to explore how work and school activities of emerging adults with and without intellectual disability relate to their social capital, as work and school settings provide increased opportunities to meet other people and foster social relationships beyond the nuclear family (Van Asselt-Goverts *et al.* 2013), while available social capital may also increase work and schooling opportunities (Timmons *et al.* 2011). An examination of factors associated with social capital is important, as it may lead to valuable insights into the need and opportunities for social capital creation for people with mild intellectual disability.

Furthermore, the only information available about the FNM-ID currently is the face validity of the findings in previous studies and that participants are able to meaningfully complete the process (Giesbers *et al.* 2019; Giesbers *et al.* 2020). Free recall techniques of network data have generally shown good scores of reliability and validity (Ferligoj and Hlebec 1999), and the original FNM has demonstrated test–retest reliability (Monney 2007). Future studies should further evaluate the psychometric properties of the FNM-ID.

Finally, to avoid priming participants' definition of their family, examples of relationship types that could be included in the family network are not provided during the FNM-ID. As concrete thinking might have

been more prevalent among participants with mild intellectual disability (Finlay and Lyons 2001), the lower number of friends in their family networks could be related to the fact that friends do not fit the traditional definition of 'family', and, therefore, were less likely to be included in the networks of young people with mild intellectual disability. In future research, this point could be examined by giving all participants information about who they might consider to be family. This potential effect of concrete thinking is clearly not universal for those with intellectual disability because 10 (18.9%) participants with intellectual disability included at least one family member that did not fit the traditional definition by including friends, neighbours, friends of parents and their parents' support staff. Also, when adapting the FNM for use with people with mild intellectual disability (Giesbers *et al.* 2019), the explanation used in the original FNM (Widmer *et al.* 2013) about 'significant family members' turned out to be too complicated and confusing for people with mild intellectual disability. Therefore, the explanation about 'significant family members' was omitted from the FNM-ID, enabling participants to give their own interpretation of significance. The Dutch word ('belangrijk') used in the FNM-ID is a simpler, more straightforward construct than the English translation 'significant' and the right terminology in English for people with mild intellectual disability might be closer to 'important to you'.

Despite these limitations, this study adds to family support and social capital theory by demonstrating how the family support experiences of young adults with mild intellectual disability differed from those of people without disabilities. Thereby, this study stresses the importance of examining the self-reported support experiences of people with mild intellectual disability. It not only examined how emerging adults defined their broad family group but also how they perceived that their relationships within their family were intertwined. Therefore, this study provides a broader understanding of the networks of people with mild intellectual disability by examining the network structures in which they are embedded. For example, we have not simply replicated findings concerning a lack of peer relationships, but also shown how this lack may have contributed to different network structures for people with mild intellectual disability, and the social capital available to them.

## Acknowledgements

We would like to thank the individuals who participated in this study and the staff from the service providers and educational institutions who supported recruitment to the research.

## Source of funding

The research was funded by service providers Dichterbij and ASVZ. Dichterbij and ASVZ have not imposed any restrictions on free access to or publication of the research data.

## Conflicts of interest

All authors declare that they have no conflict of interest.

## References

- Aeby G., Widmer E. D. & De Carlo I. (2014) Bonding and bridging social capital in step- and first-time families and the issue of family boundaries. *Interpersona* **8**, 51–69.
- Aquilino W. S. (2006) Family relationships and support systems in emerging adulthood. In: *Emerging Adults in America: Coming of Age in the 21<sup>st</sup> Century* (eds J. J. Arnett & J. L. Tanner), pp. 193–217. American Psychological Association, Washington, DC.
- Arnett J. J. (1998) Learning to stand alone: the contemporary American transition to adulthood in cultural and historical context. *Human Development* **41**, 295–315.
- Arnett J. J. (2000) Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychologist* **55**, 469–80.
- Arscott K., Dagnan D. & Stenfort Kroese B. (1998) Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **11**, 77–83.
- Borgatti S. P., Everett M. G. & Freeman L. C. (2002) *Ucinet 6 for Windows: Software for Social Network Analysis [Computer software]*. Analytic Technologies, Harvard, MA.
- Bourdieu P. (1986) The forms of capital. In: *Handbook of Theory and Research in the Sociology of Education* (ed. J. Richardson), pp. 241–568. Greenwood Press, New York.
- Bullen, P. & Onyx, J. (1999). *Social capital: family support services and neighbourhood and community centres in NSW*. Family support services NSW and neighbourhood and community centres in NSW, Sydney.
- Burt R. (1995) *Structural Holes. The Social Structure of Competition*. Harvard University Press, Cambridge, MA.
- Callus A. (2017) 'Being friends means helping each other, making coffee for each other': Reciprocity in the friendships of people with intellectual disability. *Disability and Society* **32**, 1–16.

- Carruth A., Tate U., Moffett B. & Hill K. (1997) Reciprocity, emotional wellbeing, and family functioning as determinants of family satisfaction in caregivers of elderly parents. *Nursing Research* **46**, 93–100.
- Centraal Bureau voor de Statistiek (2017) Leerlingen, deelnemers en studenten; onderwijssoort, woonregio [Pupils, participants, and students; type of education, area of residence]. Available at: <http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=71450NED&D1=0&D2=a&D3=7&D4=0-6,8,16-17&D5=0&D6=0&D7=10-14&HD=150909-0907&HDR=T,G2,G4,G6,G1&STB=G5,G3> (retrieved 10 September 2017).
- Cohen J. (1988) *Statistical Power Analysis for the Behavioral Sciences*. Erlbaum, Hillsdale, NJ.
- Coleman J. (1988) Social capital and the creation of human capital. *American Journal of Sociology* **94**, 95–121.
- Collins W. A. & Van Dulmen M. (2006) Friendships and romantic relationships in emerging adulthood: continuities and discontinuities: coming of age in the 21st century. In: *Emerging Adults in America: Coming of Age in the 21st Century* (eds J. J. Arnett & J. Tanner), pp. 219–34. American Psychological Association, Washington, D.C.
- Conger K. J. & Little W. M. (2010) Sibling relationships during the transition to adulthood. *Child Development Perspectives* **4**, 87–94.
- Cornwell B. (2009) Good health and the bridging of structural holes. *Social Networks* **31**, 92–103.
- Ferguson P. M. & Ferguson D. L. (1996) Communicating adulthood: the meanings of independent living for people with significant cognitive disabilities and their families. *Topics in Language Disorders* **16**, 52–67.
- Ferligoj A. & Hlebec V. (1999) Evaluation of social network measurement instruments. *Social Networks* **21**, 111–30.
- Finlay W. M. L. & Lyons E. (2001) Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment* **13**, 319–35.
- Forrester-Jones R. & Barnes A. (2008) On being a girlfriend not a patient: the quest for an acceptable identity amongst people diagnosed with a severe intellectual illness. *Journal of Intellectual Health* **17**, 153–72.
- Fraley R. C. & Davis K. E. (1997) Attachment formation and transfer in young adults' close friendships and romantic relationships. *Personal Relationships* **4**, 131–44.
- Friedman C. & Rizzolo M. C. (2018) Friendship, quality of life, and people with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities* **30**, 39–54.
- Furstenberg F. F. & Kaplan S. B. (2004) Social capital and the family. In: *Blackwell Companion to the Sociology of Families* (eds M. Richards, J. Scott & J. Treas), pp. 218–32. Blackwell Publisher, London.
- Giesbers S. A. H., Hendriks A. H. C., Hastings R. P., Jahoda A., Tournier T. & Embregts P. J. C. M. (2020) Social capital and the reciprocal nature of family relationships: the perspective of individuals with mild intellectual disability. *American Journal on Intellectual and Developmental Disabilities* **125**, 170–85.
- Giesbers S. A. H., Hendriks A. H. C., Jahoda A., Hastings R. P. & Embregts P. J. C. M. (2019) Living with support: experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **32**, 446–56.
- Giesbers S. A. H., Tournier T., Hendriks A. H. C., Hastings R. P., Jahoda A. & Embregts P. J. C. M. (2019) Measuring emotional support in family networks: adapting the Family Network Method for individuals with a mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **32**, 94–105.
- Gouldner A. W. (1960) The norm of reciprocity: a preliminary statement. *American Sociological Review* **25**, 161–78.
- Healy E., McGuire B. E., Evans D. S. & Carley S. N. (2009) Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. *Journal of Intellectual Disability Research* **53**, 905–12.
- Heller T., Miller A. B. & Factor A. (1997) Adults with mental retardation as supports to their parents: effects on parental caregiving appraisal. *Mental Retardation* **35**, 338–46.
- Kagitcibasi C. (2005) Autonomy and relatedness in cultural context: implications for the self and family. *Journal of Cross-Cultural Psychology* **36**, 403–22.
- Kawachi I. & Berkman L. F. (2001) Social ties and mental health. *Journal of Urban Health: Bulletin of the New York Academy of Medicine* **78**, 458–67.
- Kawachi I., Kennedy B. P. & Glass R. (1999) Social capital and self-rated health: a contextual analysis. *American Journal of Public Health* **89**, 1187–93.
- Liang J., Krause N. M. & Bennett J. M. (2001) Social exchange and well-being: is giving better than receiving? *Psychology and Aging* **16**, 511–23.
- 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.
- Mackenzie C. & Stoljar N. (2000) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*. Oxford University Press, Oxford.
- Matheson C., Olsen R. J. & Weisner T. (2007) A good friend is hard to find: friendship among adolescents with disabilities. *American Journal on Mental Retardation* **112**, 319–29.
- McDonald K. E., Kidney C. A. & Patka M. (2013) 'You need to let your voice be heard': research participants' views on research. *Journal of Intellectual Disability Research* **57**, 216–25.
- McPherson K. E., Kerr S., McGee E., Morgan A., Cheater F. M., McLean J. *et al.* (2014) The association between social capital and mental health and behavioural problems in children and adolescents: an integrative systematic review. *BMC Psychology* **2**, 7–23.



- Mill A., Mayes R. & McConnell D. (2009) Negotiating autonomy within the family: the experiences of young adults with intellectual disabilities. *British Journal of Learning Disabilities* **38**, 194–200.
- Milner P. & Kelly B. (2009) Community participation and inclusion: people with disabilities defining their place. *Disability and Society* **24**, 47–62.
- Monney A. (2007) *Les Configurations Familiales et le "Family Network Method" (FNM): Aspects Théoriques et Etude de Validation [Family Configurations and the "Family Network Method" (FNM): Theoretical Aspects and a Validation Study]*. University of Lausanne, Lausanne.
- Murphy K. R. & Myers B. (1998) *Statistical Power Analysis: A Simple and General Model for Traditional and Modern Hypothesis Tests*. Erlbaum, Mahwah, NJ.
- Neuman R. & Reiter S. (2017) Couple relationships as perceived by people with intellectual disability – implications for quality of life and self-concept. *International Journal of Developmental Disabilities* **63**, 138–47.
- Nouwens P. J. G., Lucas R., Smulders N. B. M., Embregts P. J. C. M. & Van Nieuwenhuizen C. (2017) Identifying classes of persons with mild intellectual disability or borderline intellectual functioning: a latent class analysis. *BMC Psychiatry*, 1–9.
- Reid C. E., Moss S. & Hyman G. (2005) Caregiver reciprocity: the effect of reciprocity, carer self-esteem and motivation on the experience of caregiver burden. *American Journal of Psychology* **57**, 186–96.
- Riumallo-Herl C. J., Kawachi I. & Avendano M. (2014) Social capital, mental health and biomarkers in Chile: assessing the effects of social capital in a middle-income country. *Social Science and Medicine* **105**, 47–58.
- Rosen J. W. & Burchard S. N. (1990) Community activities and social support networks: a social comparison of adults with and adults without mental retardation. *Education and Training in Mental Retardation* **25**, 193–204.
- Rushbrooke E., Murray C. & Townsend S. (2014) The experiences of intimate relationships by people with intellectual disabilities: a qualitative study. *Journal of Applied Research in Intellectual Disabilities* **27**, 531–41.
- Sanderson K. A., Burke M. M., Urbano R. C., Arnold C. K. & Hodapp R. M. (2017) Who helps? Characteristics and correlates of informal supporters to adults with disabilities. *American Journal on Intellectual and Developmental Disabilities* **122**, 492–510.
- Simplican S. C., Leader G., Kosciulek J. & Leahy M. (2015) Defining social inclusion of people with intellectual and developmental disabilities: an ecological model of social networks and community participation. *Research in Developmental Disabilities* **38**, 18–29.
- Tanner J. L. (2006) Recentring during emerging adulthood: a critical turning point in life span human development. In: *Emerging Adults in America: Coming of Age in the 21<sup>st</sup> Century* (eds J. J. Arnett & J. L. Tanner), pp. 21–55. American Psychological Association, Washington, DC.
- Thomas P. A. (2010) Is it better to give or to receive? Social support and the well-being of older adults. *Journal of Gerontology: Social Sciences* **65B**, 351–7.
- Thompson J. R., Bradley V. J., Buntinx W. H. E., Schalock R. L., Shogren K. A., Snell M. E. *et al.* (2009) Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities* **47**, 135–46.
- Timmons J., Hall A., Bose J., Wolfe A. & Winsor J. (2011) Choosing employment: factors that impact employment decisions for individuals with intellectual disabilities. *Intellectual and Developmental Disabilities* **49**, 285–99.
- Tipton L. A., Christensen L. & Blacher J. (2013) Friendship quality in adolescents with and without an intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **26**, 522–32.
- United Nations (2006) *Convention on the rights of persons with disabilities*. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (retrieved May 2018).
- 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.
- Walmsley J. (1996) Doing what mum wants me to do: looking at family relationships from the point of view of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **9**, 324–41.
- Walter J. K. & Friedman Ross L. (2014) Relational autonomy: moving beyond the limits of isolated individualism. *Paediatrics* **133**, 16–23.
- Wechsler D. (2011) *Wechsler Abbreviated Scale of Intelligence-Second Edition (WASI-II)*. NCS Pearson, San Antonio, TX.
- Wechsler D. (2012) *Wechsler Adult Intelligence Scale*, Fourth Dutch edn. Pearson Assessment and Information BV, Amsterdam.
- Widmer E. D. (2016) *Family Configurations: A Structural Approach to Family Diversity*. Routledge, Abingdon, United Kingdom.
- Widmer E. D., Kempf N., Sapin M. & Galli-Carminati G. (2013) Family beyond parents? An exploration of family configurations and psychological adjustment in young adults with intellectual disability. *Research in Developmental Disabilities* **34**, 207–17.
- Widmer E. D., Kempf-Constantin N., Robert-Tissot C., Lanzi F. & Galli Carminati G. (2008) How central and connected am I in my family? Family-based social capital of individuals with intellectual disability. *Research in Developmental Disabilities* **29**, 176–87.
- Woolcock M. (1998) Social capital and economic development: towards a theoretical synthesis and policy framework. *Theory and Society* **27**, 151–208.

Accepted 27 June 2020