ORIGINAL ARTICLE

WILEY JARID

Measuring emotional support in family networks: Adapting the Family Network Method for individuals with a mild intellectual disability

Sanne A. H. Giesbers[1,2]* iD | Tess Tournier[1,3]* iD | Lex Hendriks[4] |
Richard P. Hastings[5,6] | Andrew Jahoda[7] iD | Petri J. C. M. Embregts[1] iD

[1]Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands

[2]Dichterbij Innovation and Science, Gennep, The Netherlands

[3]ASVZ, Sliedrecht, The Netherlands

[4]Faculty of Social Sciences, School of Pedagogical and Educational Science, Radboud University Nijmegen, Nijmegen, The Netherlands

[5]Centre for Educational Development, Appraisal and Research, University of Warwick, Coventry, UK

[6]Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, School of Clinical Sciences at Monash Health, Monash University, Melbourne, Australia

[7]Psychological Medicine, University of Glasgow, Glasgow, UK

Correspondence
Sanne Giesbers, Tilburg University, P.O. Box 90153, 5000 LE Tilburg, The Netherlands.
Email: s.a.h.giesbers@tilburguniversity.edu

Funding information
The research was funded by service providers ASVZ and Dichterbij.

Abstract

Background: Informal supportive networks of individuals with intellectual disability have become increasingly important. The aim of this paper is to describe how the Family Network Method – Intellectual Disability (FNM-ID) offers a way to gather the perspective of people with mild intellectual disability on their family support.

Method: The FNM is designed to explore how individuals define their family contexts, and more specifically how they perceive existing supportive relationships in these contexts.

Results: By carefully piloting ways of questioning people with mild intellectual disability, systematic adaptations were made to the original FNM. Data obtained by the FNM-ID can be analysed using social network analysis. Thereby, the FNM-ID provides rich, theoretically significant information on emotional support in the family networks of individuals with mild intellectual disability.

Conclusions: The FNM-ID is a useful and successfully adapted tool for other researchers and professionals to systematically explore the family support experiences of individuals with mild intellectual disability.

1 | INTRODUCTION

In recent years, participation and social inclusion have dominated the policy discourse in the field of Intellectual Disability within western society. To enhance participation and social inclusion, and thereby the quality of life of individuals with intellectual disability (Schalock, 2004), a supportive social network is essential (Simplican,

Leader, Kosciulek, & Leahy, 2015). As a result, an emphasis has been placed on forging stronger links with their local community to increase and strengthen informal networks of support (e.g., Hewitt, Nord, Bogenschutz, & Reinke, 2013). In line with these changing societal views, researchers have paid increasing attention to the social networks of individuals with intellectual disability. Several studies have examined the characteristics of their social networks, showing

that the networks of the majority of individuals are relatively small (Lippold & Burns, 2009), that friendships are often formed with other people with disabilities and that interactions between individuals with intellectual disability and those in the wider community may be mainly restricted to family members (Forrester-Jones et al., 2006; Robertson et al., 2001; Van Asselt-Goverts, Embregts, & Hendriks, 2013, 2015; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009).

Even though informal networks of individuals with intellectual disability are found to mainly consist of family members, research on family support provided to them has been scarce. For several decades, research has mainly focused on the impact of having a child with intellectual disability on parental wellbeing and family quality of life (Hastings, 2016). It has been extensively shown that parental and family outcomes are influenced by many factors such as child characteristics, parents' cognitive styles, and family and environmental features. More specifically, social support, especially support from family members, is an important contributing factor to positive outcomes for parents of a child with intellectual disability (Canary, 2008; Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2014; Hassall, Rose, & McDonald, 2005; Hastings, Allen, McDermott, & Still, 2002; Shin, 2002; White & Hastings, 2004). However, studies on the provision of family support including directly the perceptions of individuals with intellectual disability have been rare. Research has shown that the actual amount of support may be of less importance for positive outcomes than the supported person's perception of the helpfulness of the support (Shin, 2002; White & Hastings, 2004), which also highlights the necessity of directly exploring the support experiences of individuals with intellectual disability themselves (Embregts, 2011; McDonald, Kidney, & Patka, 2013). Within the literature, support is often differentiated into emotional and instrumental support. Perceived emotional support is regarded as the most significant type of support and found to be a stronger predictor for positive physical and mental health-related outcomes than instrumental support (Berkman, 1995; Thoits, 1995; Viswesvaran, Sanchez, & Fisher, 1999). Also, people have been found to attribute an emotional meaning to supportive behaviours that are instrumental in nature. In other words, by providing instrumental support, someone may show that they are being caring and have an understanding of another person's needs (Semmer et al., 2008).

Various instruments have been used to examine social network characteristics of individuals with intellectual disability, such as the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994), the Social Network Guide (SNG; Forrester-Jones et al., 2006), the Social Support Self Report (SSSR; Lippold & Burns, 2009; Lunsky & Benson, 1997), the Social Network Questionnaire (Dagnan & Ruddick, 1997; Krauss & Erickson, 1988), the Support Interview Guide (SIG; Llewellyn & McConnell, 2002), the Functional Support Inventory (FSI; Felton & Berry, 1992; Lippold & Burns, 2009) and the Hierarchical Mapping Technique (Circles Task) (Antonucci, 1986; Lippold & Burns, 2009). Using these existing instruments, researchers have been able to provide detailed information on social network

characteristics, including the views of individuals with intellectual disability themselves. The instruments were used to examine the supportive relationships that existed between the person with intellectual disability and his/her network members. Most of these instruments focused on support received by the person with intellectual disability (Antonucci, 1986; Dagnan & Ruddick, 1997; Felton & Berry, 1992; Llewellyn & McConnell, 2002). Some instruments (i.e., Social Network Map, SSSR, and the SNG) also examined the support that was given by the person with intellectual disability to his/her network members, assessing the reciprocal character of the person's supportive relationships (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001).

However, none of the existing social network instruments have examined the supportive relationships existing among all network members of the person with intellectual disability. Relationships between a person and his/her network members cannot be seen as isolated from the broader social context. Until know, research has often disregarded the social context of interdependencies among network members of individuals with intellectual disability in which, for example, intimate relationships, close friendships or parent–child relationships are embedded. In addition, none of the methods listed above have a specific focus on assessing the family networks of people with intellectual disability—although all would potentially capture elements of support from family members.

An instrument that has been developed to explore how individuals define their family contexts, and more specifically how they perceive existing supportive relationships in these contexts, is the Family Network Method (FNM; Widmer, Aeby, & Sapin, 2013). In line with a trend in sociological research, the FNM has conceptualized family relationships within the theory of social capital (Furstenberg & Kaplan, 2004; Widmer, 2006, 2007, 2016). Social capital is defined as recourses that flow to individuals from their membership of a durable social network (Bourdieu, 1986). From this perspective, family relationships (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 & Berkman, 2001; Kawachi, Kennedy, & Glass, 1999; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). The main types of social capital, bonding and bridging social capital (Burt, 1995; Coleman, 1988) are relevant with respect to family networks. Bonding social capital refers to network closure (i.e., a group with a high density of connections and redundant ties) (Coleman, 1988). As dense networks enhance expectations, obligations and trust among its members, support within such a network becomes collective. Traditionally, family relationships have been regarded as bonding social capital, based on the assumption that the significant family is constituted by the nuclear family (i.e., married couples and their children). However, this focus on the nuclear family ignores the fact that, due to the pluralization of life courses in late-modernity, family contexts have become more heterogeneous and open (Allan, 2008; Widmer, 2016). More recently, it has been shown that family contexts based on blood ties mostly provide a bonding type of social capital, whereas family

contexts based on friendships usually provide bridging social capital (Widmer, 2006, 2007). Bridging social capital refers to weaker connections between subgroups of a network that give some individuals (i.e., brokers) the potential to mediate the flow of resources between group members (Burt, 1995). To examine the social capital that is provided by the family, FNM respondents are not only asked about their own relationships with family members, but also about their views of relationships among the different family members who make up their network. Thereby, the FNM provides a better understanding of the family context of structural interdependencies in which individuals and their close family relationships are embedded. As the FNM captures respondents' perceptions of how their family networks are organized in terms of, for example, support provision, the FNM might be a useful instrument to question individuals with intellectual disability about their family support experiences, thereby examining the social capital their families provide.

However, the FNM was developed for use in the general population. Although there is evidence that individuals with a mild intellectual disability can be reliable informants of their support experiences (Lunsky & Benson, 1997), the instrument cannot be automatically applied to them. As a result of cognitive and language impairments, they might experience difficulties in understanding questions and communicating valid and reliable answers when using instruments developed for people without disabilities (Coons & Watson, 2013; Finlay & Lyons, 2001). Yet it has been generally recognized that individuals with intellectual disability have a valid perspective on their lives and several suggestions for questioning them in a reliable and valid way have been made in the literature (Perry, 2004). The FNM has previously indeed been used with individuals with mild intellectual disability (Widmer, Kempf, Sapin, & Galli-Carminati, 2013; Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Galli Carminati, 2008). However, the exact procedure that has been used to question them has not been reported. To enhance the method's transparency and transferability for use in the population of individuals with intellectual disability, it is important to systematically report the procedures used and to document the adaptations that have been made to facilitate their understanding. Therefore, the first aim of this study was to describe how systematic adaptions have been made to the FNM, by carefully piloting ways of questioning individuals with mild intellectual disability about their family networks, making the FNM a useful and reliable tool for other researchers and professionals. The second aim of this study was to give a detailed description of the data that could be obtained by the FNM.

2 | THE ORIGINAL FAMILY NETWORK METHOD

The original FNM consists of three parts, and a detailed description is shown in Table 1. In the first part, participants are asked to list their significant family members. The term "family member" is deliberately left undefined, to allow participants to decide whom they consider as family and may wish to include as significant family members. Participants are told that the term "significant" refers to those family members who have played a role in their life, either positive or negative, during the past year (Widmer, 2006). In the second part of the FNM, participants are asked about their perceptions of the relationships between the family members they have identified. Four aspects of the relationships between family members are examined: emotional support, instrumental support, influence and conflicts. In the third part, socio-demographic information is collected about each listed family member, as well as information on the nature of the family tie, the duration of the relationship and the frequency of contact.

2.1 | Family Network Method—intellectual disability: revised content and procedures

To adapt the FNM for use with individuals with intellectual disability, two pilot studies were carried out, involving a total of 19 participants with a mild (*n* = 16) or moderate (*n* = 3) intellectual disability. Participants had a mean age of 32.7 years (*SD* = 13.14, range 19–65 years) and 13 were male. The vast majority (*n* = 13) of participants lived in community-based settings, whereas six lived in residential, more segregated, facilities. This early testing suggested that asking people with intellectual disability about multiple dimensions of support would be overly complex and may not lead to different information for each dimension. For example, difficulties arose in differentiating instrumental from emotional support. The nature of the wording might not have been understood by people with intellectual disability when trying to explain instrumental support. Also, piloting showed that focusing only on emotional support already placed a high time demand on participants. As perceived emotional support is also regarded as the most significant type of support (Berkman, 1995; Thoits, 1995; Viswesvaran et al., 1999), the initial question about family relationships focussed on emotional support only. Therefore, during the pilot interviews, participants were asked to examine the relationships among their family members in relation to emotional support provision: "Who would give emotional support to X (i.e., each individual included in the participant's family configuration, considered one by one) during routine or minor troubles?" (Widmer, Aeby et al. 2013).

Before the pilots were carried out by the first two authors of this study, the original FNM was translated into Dutch using a systematic forward-backward translation procedure (Cull et al., 2002). In addition, instructions for the interviewer were added to standardise the interview procedure. During the pilot interviews, one researcher was the interviewer, the second researcher observed and made notes about the procedure and difficulties that occurred during the interview. After the interview, these notes were documented in a log. The duration of the interviews varied between 15 minutes and two hours, depending on how many family members were listed, and the participant's understanding of the questions, which varied according to their level of intellectual disability and ability to concentrate.

Based on the experiences of these pilot interviews, as well as the suggestions of Finlay and Lyons (2001) about overcoming difficulties when interviewing people with intellectual disability, adaptations were made to the original instrument.

2.2 | Interview procedure

The FNM-ID is carried out individually with the participant at a place of their choosing, to ensure the participant's privacy and to facilitate a congenial atmosphere which might contribute to a feeling of safety. At the start of the interview, the interviewer initiates "small talk" with the participant, in which specific questions about the family network are asked. For instance, questions with respect to significant others in the participant's living situation, leisure time and work. This small talk helps to make the participant feel comfortable and allows the interviewer to develop a picture of the participants' life and gain an initial insight into significant others in his/her network. The interviewer is able to start with the first question of the FNM-ID after observing that the

TABLE 1 Original FNM and FNM-ID: description, differences and rationale of adaptations

Topic	Original FNM	FNM-ID	Rationale for adaptations
FNM guide in general	Names of family members are written down on a list.	-Cards are used to write down the names of the family members -Demographics are written on the back of the cards -Green and red boxes are used to differentiate first between significant and not significant family members and later between family members who provide support and those who do not provide support.	Supportive (visual) techniques were added to the protocol. According to Boster (1994) a card sorting method makes it easier to judge the similarities among large numbers of items. The names of the listed family members were written down on small paper cards (one card for each person) so they can be presented on the table to give a better overview of the listed family members compared to writing down a list of names. As demonstrated in earlier studies (e.g., Forte, Jahoda, & Dagnan, 2011; Pownall, Wilson, & Jahoda, 2017), asking the participants to select and post the cards helped to scaffold their task and ensure they were making active judgements. Also, the cards put the participant more in charge of the decision making. A red and a green box were used to support answering the questions and to ensure participants are making active choices and to make the choice more tangible.
Start of the interview	Officially not in the original FNM guide	-Start small talk with the participant. Specific questions about the family network are asked. For instance, significant others in the living situation, leisure time or work.	
Introductory talk about family	Officially not in the original FNM guide	1. Talk about the family network, give instruction and ask the two following questions: -I would like to talk to you about your family. You define for me who you consider to be your family. -Could you tell me about your nuclear family? Who is in your nuclear family[a]? -Could you tell me about your extended family? With whom do you have contact (in some way)?	During the pilot the researchers noticed that participants would think more about family members they recently saw or spoke to instead of their whole family. Therefore, an introduction to the FNM was added, in which participants were asked to talk about their family. The aim of establishing rapport and opening up the topic of family more broadly was to ensure that participants would think about their whole family when answering the question "who is in your family?" and not just people they saw lately. Also, the instruction "you tell us who you think of as family" was added to the first question because the researchers were interested in finding out about the participants' own definition of family.

(Continues)

TABLE 1 (Continued)

Topic	Original FNM	FNM-ID	Rationale for adaptations
Defining significant family members	Respondents are first asked to give a list of persons that they consider as significant family members. They are instructed that the term "significant" refers to those people in their family who have played a role, either positive or negative, in their life during the past year. A statement is read to respondents that further emphasizes that they should not only refer to the people of their family who are significant to them because they love them or respect them, but also to those who have upset them or have made them angry during the last year. The term "family" is left undefined and respondents are asked to use their own definition of what they intend by "family."	2. Define the significant family members: 　2.1. Which members of your family are significant to you? It could be no one, a few or all of them, it is up to you how many people you chose. 　2.2. Who among them means a lot to you? 　2.3. Who is always there for you? Strategy A: -Ask the participant permission to take a picture of him/her. -If "yes": take a picture and print this picture. If "no": a pictogram of a man/woman is shown to the participant. The interviewer explains that the image represents the participant. -The participant is asked to put the cards of the family members that are most significant/closest to him/her next to the image. -If the participant is not able to indicate the most significant people, ask for the most significant five. -If the participant is not able to indicate the most significant five people, ask them one by one (e.g., who the foremost significant person is/who is number one, who else is significant?) Strategy B: -Ask the participant about a significant event. -Ask the participant: if this event takes place, who of your family members should definitely come/be there? -If the participant is not able to list the most significant people, ask for the most significant five. If the participant is not able to list the most significant five people, ask them one by one (e.g., who is foremost significant person/who else, etc.)	We noticed that the explanation about "significant family members" was too complicated and confusing for people with intellectual disability. Participants asked for further explanation before they were able to answer the question. Therefore, the explanation about "significant" family members ("Significant refers to people who have played a role, either positive or negative, in your life during the past year") was omitted from the adapted approach, enabling participants to give their own interpretation of significance. When defining the significant family members, the instruction "it could be no one, a few or all of them, it is up to you how many people you chose" was added. During the second pilot, the interviewers experienced that participants sometimes already made a selection when listing their family members (i.e., participants did not list their whole family but just a selection of significant members). By adding the instruction that all family members could be considered significant, the researchers tried to avoid over-selecting significant family members. Furthermore, the instruction that none of the family members could be considered significant is added to decrease the chance of social desirable answers.
Emotional support	Who would give emotional support to X during routine or minor troubles? (E.g.: when X is sad, when X had a bad day, who would help him/her, console him/her, etc.)(The original FNM asks these questions only about significant family members).	3.Defining the emotional support of relationships: 　3.1. If X is feeling out of sorts, who is there for X? 　3.2. If X is not having such a good day, who supports X? 　3.3. If X is feeling out of sorts, who listens to X? 　3.4. If X is feeling out of sorts, who reassures X? Strategy C: -Ask: Does X ever feel out of sorts? -Ask the participant to think back and tell about the last time that happened. -Ask about the persons who supported X in that situation. -Ask about persons who help X in similar situations.	

TABLE 1 (Continued)

Topic	Original FNM	FNM-ID	Rationale for adaptations
Demographic questions	-Gender -Age -Level of education -The nature of the family tie -The duration of the relationship -Where does the person live -Frequency of contact face-to-face -Frequency of contact in other ways (telephone, internet)	-Gender *Is X male or female?* -Age (categorised into decades) *How old is X?* -Nature of the family tie *What is your family tie with X?* -Duration of relationship → only if the participant lists someone who isn't a family member (categorised into decades) *For how long have you known X?* -Place of residence *Does X live in the same village/city as you?* -Frequency of contact (categorised: every day, every week, every month, less than once a month, never) *How often do you see X face-to-face?* *How often do you have contact with X in other ways? (Telephone, internet)*	Answering the questions about demographics was found to be difficult for people with intellectual disability. The researchers noticed that participants were not able to answer the questions precisely which, in some cases, made them feel insecure and irritated. Since a rough estimation about these characteristics is sufficient enough, categories were made for the demographic questions about age, duration of the relationship, place of residence and frequency of contact. The question about level of education of family members appeared to be too difficult to answer for most participants; therefore, it was decided to eliminate this question.
Significance of the person with intellectual disability	Officially not in the original FNM guide	4. Defining significance of the person with intellectual disability to the family members: 4.1. To which of your family members are you significant? It could be no-one, a few or all of them, it is up to you how many people you chose. 4.2. To whom do you mean a lot? 4.3. For whom are you always there?	As it might also be valuable to measure another element of the reciprocity of significance within relationships, a new question was added at the end of the interview; the participant is asked to whom they thinks they are a significant other.

[a]In Dutch, the word "gezin" is used for the nuclear family, a commonly used word, which typically refers to parents and their children. The right terminology in English for individuals with mild intellectual disability needs some further thought.

participant is at ease. The first question of the FNM-ID is to talk about the family network:

1. I would like to talk to you about your family. You define for me who you consider to be your family.
   Could you tell me about your nuclear family? Who is in your nuclear family?
   Could you tell me about your extended family? With whom do you have contact (in some way)?

The interviewer writes all the names of the listed family members down on separate cards, starting with the name of the participant. On every card, a number is written as well (the participant is always number one, the first listed person is number two, the second listed person is number three, etc.), which corresponds with the number on the scoring form. If the participant mentions demographic information when talking about a person, the information is noted on the back of that person's card. The interviewer tells the participant that the names of listed family members will not be used for research; every single person receives a code after the interview and the data are processed anonymously.

The second question is about defining the significant family members from those listed at the first stage:

2. Which members of your family are significant to you? It could be no-one, a few or all of them, it is up to you how many people you chose.

   2.1. Who among them means a lot to you?
   2.2. Who is always there for you?

The interviewer checks whether the family members on the cards are considered to be significant by showing the cards (one by one) to the participant. A green and a red box are used to support the participant; cards for family members who are considered significant are put in the green box, the cards of the family members who are considered not significant, are put in the red box. Alternative questions (for example question 2.1 and 2.2) can be asked (in a fixed order) when a participant is not able to answer the main question. If these additional questions are not sufficient, strategies can be used to help participants to answer the question (see Table 1). These questions and strategies were added to standardize the procedure of the FNM-ID and to enhance the reliability of the instrument. Subsequently, all the cards in the green and red box are put back on the table again and the interviewer moves on to the third question, which is about emotional support. This question concerns whether a participant receives and/or gives emotional support to his/her listed

persons; and whether emotional support is provided among all the listed people.

3. If X is feeling out of sorts, who is there for X?

    3.1. If X is not having such a good day, who supports X?
    3.2. If X is feeling out of sorts, who listens to X?
    3.3. If X is feeling out of sorts, who reassures X?

The interviewer checks whether the family members give emotional support to the participant by showing the cards (one by one) again to the participant. Again, the red and green box are used to support the participant and additional questions are available. After this is completed, the participant is asked to provide his/her perceptions of the relationships among the network members, answering the same questions about emotional support for every single person (using the same procedure with the cards and the boxes). If the main question or the additional questions are not sufficient to obtain answers, strategy C can be used (see Table 1). After this, demographics of all the listed people are collected and written on the back of the card of the concerning person. Table 1 provides an overview of the demographic data collected.

Finally, a fourth question about significance of the participant to his/her family members is asked:

4. To which of your family members are you significant? It could be no one, a few or all of them, it is up to you how many people you chose.
    4.1. To whom do you mean a lot?
    4.2. For whom are you always there?

The interviewer checks whether the participant considers themselves significant to every family member in the network by showing the cards of all members (one by one) to the participant. Again, additional questions (4.1 and 4.2) are available in case the main question is not sufficient, and the boxes are used.

Based on these two pilots, Table 1 summarizes, per topic, the adaptations and rationale of adaptations between the original FNM and the FNM-ID.

3 | SOCIAL NETWORK MEASURES OBTAINED FROM THE FNM-ID

In this part of the study, we will illustrate the measures that give insight into people with mild intellectual disability's perceptions of their family configurations, based on the data obtained from the FNM-ID. As in the original FNM, analysis concerns the significant family network (family members that are selected at step two of the FNM-ID). Different software packages can be used to analyse social network data, for example UCINET (Borgatti, Everett, & Freeman, 2002) or R software packages like statnet (Handcock et al., 2016). Using these packages, measures can be calculated for the significant family network of the participant as a whole (network measures) or

for specific persons in the network (centrality measures). Network measures give a better understanding of family configurations of people with mild intellectual disability, whereas centrality measures give information about how individual family members are located or embedded in the overall family network (Hanneman & Riddle, 2005).

1. *Network measures.* Several measures about the family network can be calculated: that is, size, density, average degree, arc reciprocity and index of components. The size of the network represents the number of family members listed by the participant. Density of a network can be calculated by dividing the number of supportive ties (connections) among all the family members by the maximum number of potential supportive ties if all the family members were connected. In highly dense connected family networks, most or all family members are connected with each other, providing a bonding type of social capital. Average degree calculates the average number of supportive ties of the family members in a network; it divides the total number of supportive ties that exist in the network by the number of network members. The arc reciprocity represents the proportion of reciprocal relationships within a network: of all the support that is given from one family member to another, what proportion is reciprocated? The "index of components" measures how many subgroups there are in a network.

2. *Centrality measures.* Per family member, centrality measures can be computed, qualifying the position of a person in a network. The degree centrality of a family member refers to the number of supportive ties a person has. This measure can be specified as in- or out-degree. The in-degree of a person is the number of supportive ties that represent the support received from other family members. The out-degree is the number of support ties in which a person gives support to other family members in the network. Betweenness centrality describes the intermediary position of a person in the family network. Betweenness centrality is about how many pairs of family members would have to go through to the person in order to reach one another (in the minimum number of hops). Family members with a high betweenness centrality mediate the flow of support among network members, providing a bridging type of social capital.

3. *Attribute measures.* The FNM-ID obtains demographic information of all the listed family members and the person with intellectual disability: these data are called attributes. Attributes are calculated for either the full family network (e.g., 40% of the family network is male) or the nodes' in- or out-degree (e.g., 10% of the people who provide support live in the same place of residence).

4. *Graphs.* Networks can be visualized using a variety of software methods including NetDraw (part of the UCINET software package). The network and centrality measures can be combined with attributes and can be visualized using different colours, shapes or sizes.

4 | FNM-ID NETWORKS: TWO ILLUSTRATIVE CASES

Two cases have been selected to illustrate possible differences between family configurations of people with mild intellectual diability and the potential utility of the FNM-ID. Pseudonyms are used to protect anonymity. The first case describes the family configuration of a 27-year-old male (Bob) living in the community in the Netherlands. He received support within a clustered care setting and had set times for one-to-one support, but he was able to ask for additional support at any time during a 24-hour period. This participant listed five family members at step one of the FNM-ID; his father, mother and three uncles. According to Bob, two of his uncles did not have an emotional support connection to anyone in the network (no arcs are pointing to or from the uncles). Bob only considered his parents as significant (see Figure 1). The size of Bob's significant network was three (see Table 2); Bob, his father and his mother who were also the members who provided him with emotional support (the in-degree measure for Bob was 2). Bob was not supporting his parents in return (out-degree measure is 0, arc reciprocity is 0.00). As there are no reciprocal supportive
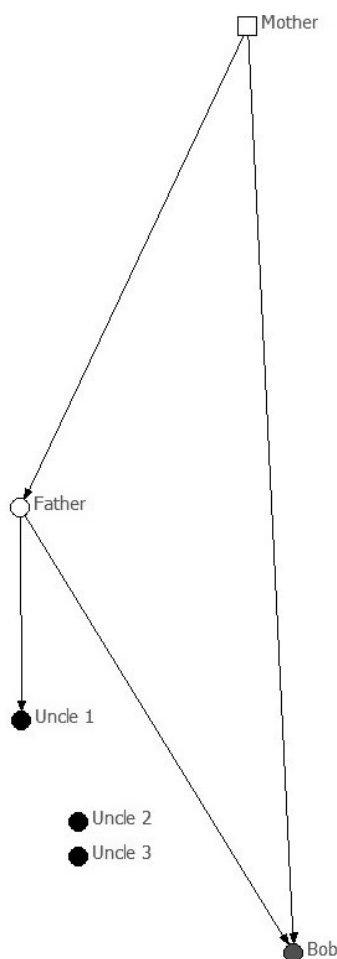
relationships in the significant network, the density has a score of 0.50.

Due to the little support among the family members, the average degree of the network is 1.00. The betweenness centrality for Bob is 0.00, indicating that he is not an intermediary for the other network members.

The second case is of a 33-year-old female (Mary), also living in a clustered care setting in the community in the Netherlands. At step one of the FNM-ID, she listed her mother, father, two sisters, two brother-in-laws and her two nephews. Except for one brother-in-law, Mary considered all of them as significant, making the size of the significant network eight. Mary has a quite dense network (Figure 2). Figure 2 shows that Mary has three emotional relationships that are reciprocal (see two sided arcs), with her mother and with her two sisters. Her father is giving her emotional support as well, but Mary feels that she is not supporting him. According to Mary, the other listed family members are emotionally supported by other family members. For example, her mother is supported by the father, sister 1 and 2, Mary herself and brother-in-law 1.

As a result of the large number of supportive relationships between the family members, the density score of this network is 0.66 (Table 2). As previously indicated, the density can be calculated by dividing the number of ties (connections) among the nodes by the maximum number of potential ties. As a result, the score will always vary between 0 (no support between family members) and 1 (all family members are supporting each other). Therefore, a score of 0.66 indicates a relatively high density. Because of this supportive network, the average degree is 4.63, and many of these supportive relationships are reciprocal (arc reciprocity is 0.70). Mary has a betweenness centrality of 0.00, meaning that no family members have to pass her to reach one another.

In addition to information about the size of a network and the supportive relationships between the family members, the attributes of the family members can also be analysed. Attributes can be, for example, age, gender, place of residence or nature of the family tie and can be calculated by the "composition." In Table 3, the network compositions with respect to the attribute "nature of the family tie" for Bob and Mary are shown. The "raw score for the whole network" represents the number of each type of family member within the significant network of the person with intellectual disability. Bob's network includes two parents (proportion of 1.00) and receives support

FIGURE 1 Family configuration for Bob. ○: male; □: female; grey: Bob; white: significant; black: not significant

TABLE 2 FNM-ID significant network measures for Bob and Mary

Measure	Bob	Mary
Network size	3	8
Density	0.500	0.661
Average degree	1.00	4.625
Arc reciprocity	0.000	0.703
Indegree	2	4
Outdegree	0	3
Betweenness centrality	0	0

from both them (proportion is 1.00) (in-degree). This network composition shows that Bob is highly dependent on his nuclear family when it comes to emotional support. This information might be valuable, for example, to understand the sustainability of his family network; when his parents pass away, there will be no other network members available who have a history of providing Bob with emotional support.

Mary's network consists of two parents, two siblings, two extended family members and one in-law family member (see Table 3 for proportion scores). Mary is supported by her two parents and two siblings and provides support (out-degree) to one parent and two of her siblings. Again, this composition shows Mary's vulnerable position in the family network. If her parents pass away, only 50% of her emotionally supportive family relationships will remain.

5 | CONCLUSION

The FNM-ID enables a systematic exploration of the way in which individuals with mild intellectual disability define their family contexts,

as well as the social capital these contexts provide. Research has neglected the direct perspectives of individuals with intellectual disability with respect to family support. Their informal supportive networks, which to a great extent, are shaped by family members, have become increasingly important in a time of austerity and cuts to services. Therefore, gaining insight into their family context may play an important role in facilitating their social participation and inclusion.

Based on thorough piloting, the original FNM has been successfully adapted to better suit the cognitive and linguistic needs of individuals with mild intellectual disability (Finlay & Lyons, 2001). Although the intention was to include people with a moderate intellectual disability in these developments, in our piloting the instrument remained too complex despite the adaptations. In particular, these participants found taking the perspective of another family member too complicated and cognitively challenging. This finding might be due to the degree of their disability. Future research should explore ways of questioning people with moderate intellectual disability about their family networks.
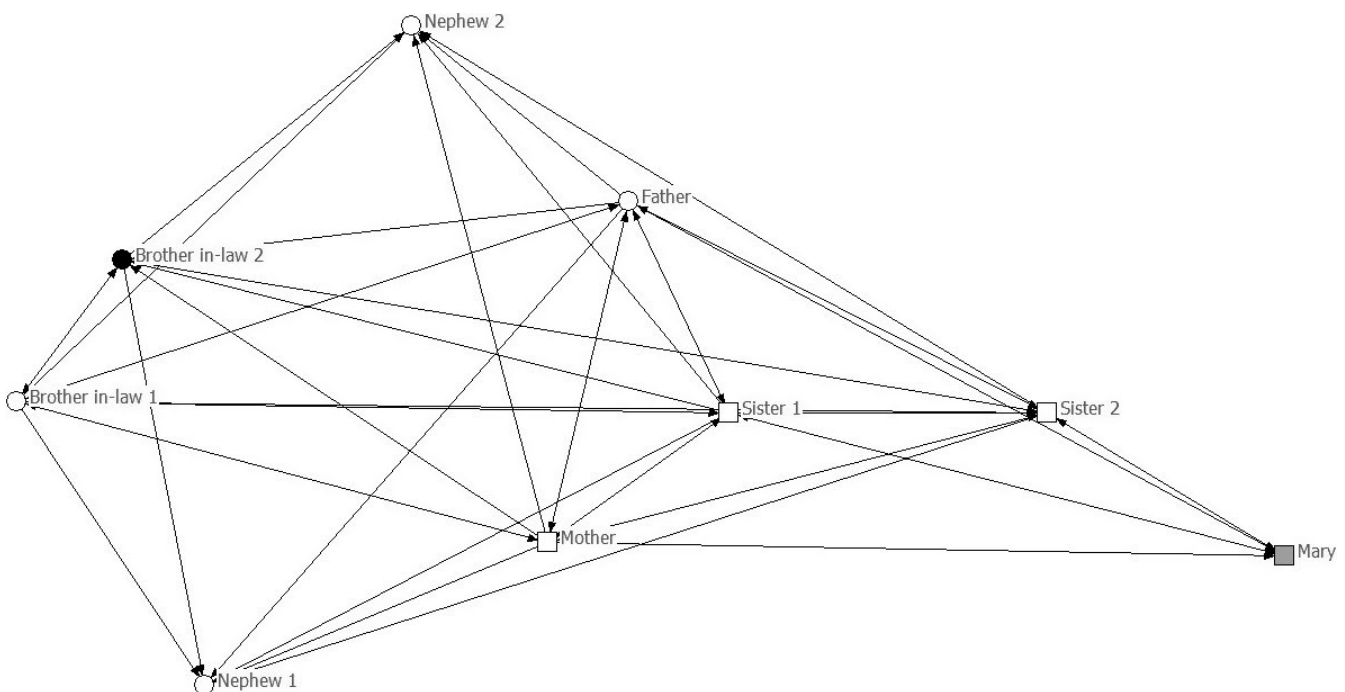

FIGURE 2 Family configuration for Mary. ○: male; □: female; grey: Mary; white: significant; black: not significant

TABLE 3 Significant network composition attribute "nature of the family tie" for Bob and Mary

Attribute	Participant		Whole network raw score (proportion)	In-degree raw score (proportion)	Out-degree raw score (proportion)
Nature of the family tie	Bob	Parent	2 (1.00)	2 (1.00)	0 (0.00)
	Mary	Parent	2 (0.29)	2 (0.50)	1 (0.33)
		Sibling	2 (0.29)	2 (0.50)	2 (0.67)
		Extended family	2 (0.29)	0 (0.00)	0 (0.00)
		In-law family	1 (0.14)	0 (0.00)	0 (0.00)

The FNM-ID not only offers a way to gather the perspective of people with mild intellectual disability about their family support, but also provides rich, theoretically significant information about their family networks. In addition, the FNM-ID provides information about the person's perception of the relationships among all family network members. Thus, the FNM-ID provides a broader understanding of the family context of structural interdependencies in which individuals with mild intellectual disability and their close family relationships are embedded (Widmer, Aeby et al., 2013). Findings of earlier family research have already shown that supportive relationships between a person with intellectual disability and his/her family members cannot be seen as isolated from the broader family structure. More specifically, higher levels of social support for parents of children with a disability, especially support from family members, lead to more positive outcomes in those parents, who in turn, might better relate emotionally to their children (Boyd, 2002; Hastings, Thomas, & Delwiche, 2002; Trute, Worthington, & Hiebert-Murphy, 2008).

After systematically adapting the FNM for use with individuals with mild intellectual disability, the next step is to apply the FNM-ID in research in which substantial samples of individuals with mild intellectual disability are questioned about their family contexts. This is crucial to generate new knowledge on, for example, patterns of family configurations of individuals with mild intellectual disability, the type and amount of family-based social capital available to them, and the relationship between family resources and outcome measures such as the individual's subjective well-being and mental health.

CONFLICT OF INTEREST

All authors declare that they have no conflict of interest

ORCID

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

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

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

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

REFERENCES

Allan, G. (2008). Flexibility, friendship, and family. *Personal Relationships*, *15*, 1–16. https://doi.org/10.1111/j.1475-6811.2007.00181.x

Antonucci, T. C. (1986). Social support networks: Hierarchical mapping technique. *Generations*, *10*, 10–12.

Berkman, L. (1995). The role of social relations in health promotion. *Psychosomatic Medicine*, *57*, 245–254. https://doi.org/10.1097/00006842-199505000-00006

Borgatti, S. P., Everett, M. G., & Freeman, L. C. (2002). *UCINET for Windows. Software for social network analysis*. Harvard, MA: Analytic Technologies.

Boster, J. (1994). The successive pile sort. *Cultural Anthropology Methods*, *6*(2), 7–8. https://doi.org/10.1177/1525822x9400600205

Bourdieu, P. (1986). The forms of capital. In J. Richardson (Ed.), *Handbook of theory and research in the sociology of education* (pp. 241–568). New York, NY: Greenwood Press.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, *17*(4), 208–215. https://doi.org/10.1177/10883576020170040301

Burt, R. (1995). *Structural holes. The social structure of competition*. Cambridge, MA: Harvard University Press.

Canary, H. E. (2008). Creating supportive connections: A decade of research on support for families of children with disabilities. *Health Communication*, *23*, 413–426. https://doi.org/10.1080/10410230802342085

Cohen, S. R., Holloway, S. D., Domínguez-Pareto, I., & Kuppermann, M. (2014). Receiving or believing in family support? Contributors to the life quality of Latino and non-Latino families of children with intellectual disability. *Journal of Intellectual Disability Research*, *58*(4), 333–345. https://doi.org/10.1111/jir.12016

Coleman, J. (1988). Social capital and the creation of human capital. *American Journal of Sociology*, *94*, 95–121. https://doi.org/10.1086/228943

Coons, K. D., & Watson, S. L. (2013). Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*, *19*(2), 14–24.

Cull, A., Sprangers, M., Bjordal, K., Aaronson, N., West, K., & Bottomley, A. (2002). *EORTC quality of life group translation procedure* (pp. 3–15). Brussels, Belgium: EORTC.

Dagnan, D., & Ruddick, L. (1997). The social networks of older people with learning disabilities living in staffed community based homes. *British Journal of Developmental Disabilities*, *43*, 43–53. https://doi.org/10.1179/bjdd.1997.006

Embregts, P. J. C. M. (2011). *Zien, bewogen worden, in beweging komen [See, be moved, start moving]*. Tilburg, The Netherland: Tilburg University.

Felton, B. J., & Berry, C. (1992). Groups as social network members: Overlooked sources of social support. *American Journal of Community Psychology*, *20*, 253–261. https://doi.org/10.1007/bf00940839

Finlay, W. M. L., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, *13*(3), 319–335. https://doi.org/10.1037/1040-3590.13.3.319

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., ... Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, *19*, 285–295. https://doi.org/10.1111/j.1468-3148.2005.00263.x

Forte, M., Jahoda, A., & Dagnan, D. (2011). An anxious time? Exploring the nature ofworries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood. *British Journal of Clinical Psychology*, *50*, 398–411. https://doi.org/10.1111/j.2044-8260.2010.02002.x

Furstenberg, F. F., & Kaplan, S. B. (2004). Social capital and the family. In M. Richards, J. Scott, & J. Treas (Eds.), *Blackwell companion to the sociology of families* (pp. 218–232). London, UK: Blackwell Publisher.

Handcock, M., Hunter, D., Butts, C., Goodreau, S., Krivitsky, P., Bender-deMoll, S., & Morris, M. (2016). *statnet: Software Tools for the Statistical Analysis of Network Data*. The Statnet Project. Retrieved from http://www.statnet.org

Hanneman, R. A., & Riddle, M. (2005). *Introduction to social network methods*. Riverside, CA: University of California.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, *49*(6), 405–418. https://doi.org/10.1111/j.1365-2788.2005.00673.x

Hastings, R. P. (2016). Do children with intellectual and developmental disabilities have a negative impact on other family members? The case for rejecting a negative narrative. *International Review of Research in Developmental Disabilities*, *50*, 165–194. https://doi.org/10.1016/bs.irrdd.2016.05.002

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *15*, 269–275. https://doi.org/10.1046/j.1468-3148.2002.00104.x

Hastings, R. P., Thomas, H., & Delwiche, N. (2002). Grandparent support for families of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, *15*, 94–104. https://doi.org/10.1046/j.1360-2322.2001.00097.x

Hewitt, A. S., Nord, D., Bogenschutz, M., & Reinke, J. (2013). Community living. *Inclusion*, *1*, 17–27. https://doi.org/10.1352/2326-6988-1.1.017

Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, *78*(3), 458–467. https://doi.org/10.1093/jurban/78.3.458

Kawachi, I., Kennedy, B. P., & Glass, R. (1999). Social capital and self-rated health: A contextual analysis. *American Journal of Public Health*, *89*(8), 1187–1193. https://doi.org/10.2105/ajph.89.8.1187

Krauss, M. W., & Erickson, M. (1988). Informal support networks among aging persons with mental retardation: A pilot study. *Mental Retardation*, *16*, 197–201.

Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, *53*, 463–473. https://doi.org/10.1111/j.1365-2788.2009.01170.x

Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research*, *46*, 17–34. https://doi.org/10.1046/j.1365-2788.2002.00347.x

Lunsky, Y., & Benson, B. A. (1997). Reliability of ratings of consumers with mental retardation and their staff on multiple measures of social support. *American Journal on Mental Retardation*, *102*(3), 280–284. https://doi.org/10.1352/0895-8017(1997)102%3C0280:ROROCW%3E2.0.CO;2.

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*(3), 216–225. https://doi.org/10.1111/j.1365-2788.2011.01527.x

McPherson, K. E., Kerr, S., McGee, E., Morgan, A., Cheater, F. M., McLean, J., & Egan, J. (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. https://doi.org/10.1186/2050-7283-2-7

Perry, J. (2004). Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, T. Thompson, & T. Parmenter (Eds.), *International handbook of applied research in intellectual disabilities* (pp. 115–131). Sussex, UK: John Wiley & Sons Ltd.

Pownall, J., Wilson, S., & Jahoda, A. (2017). Health knowledge and the impact of social exclusion on young people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. Early Online Publication. https://doi.org/10.1111/jar.12331

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 & Medicine*, *105*, 47–58. https://doi.org/10.1016/j.socscimed.2013.12.018

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, *39*(3), 201–214. https://doi.org/10.1352/0047-6765(2001)039%3c0201:snopwm%3e2.0.co;2

Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, *48*(3), 203–2016. https://doi.org/10.1111/j.1365-2788.2003.00558.x

Semmer, N. K., Elfering, A., Jacobshagen, N., Perrot, T., Beehr, T. A., & Boos, N. (2008). The emotional meaning of instrumental social support. *International Journal of Stress Management*, *15*(3), 235–251. https://doi.org/10.1037/1072-5245.15.3.235

Shin, J. Y. (2002). Social support for families of children with mental retardation: Comparison between Korea and the United States. *Mental Retardation*, *40*(2), 108–118. https://doi.org/10.1352/0047-6765(2002)040%3C0103:SSFFOC%3E2.0.CO;2.

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. https://doi.org/10.1016/j.ridd.2014.10.008

Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior*, *35*, 53–79. https://doi.org/10.2307/2626957

Tracy, E. M., & Abell, N. (1994). Social network map: Some further refinements on administration. *Social Work Research*, *18*(1), 56–60.

Trute, B., Worthington, C., & Hiebert-Murphy, D. (2008). Grandmother support for parents of children with disabilities: Gender differences in parenting stress. *Families, Systems, & Health*, *26*(2), 135–146. https://doi.org/10.1037/1091-7527.26.2.135

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*, 1280–1288. https://doi.org/10.1016/j.ridd.2013.01.012

Van Asselt-Goverts, A. E., Embregts, P. J. C. M., & Hendriks, A. H. C. (2015). Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research*, *59*, 450–461. https://doi.org/10.1111/jir.12143

Verdonschot, M. M. L., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, *53*, 303–318. https://doi.org/10.1111/j.1365-2788.2008.01144.x

Viswesvaran, C., Sanchez, J., & Fisher, J. (1999). The role of social support in the process of work stress: A meta-analysis. *Journal of Vocational Behavior*, *54*, 314–334. https://doi.org/10.1006/jvbe.1998.1661

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17*, 181–190. https://doi.org/10.1111/j.1468-3148.2004.00197.x

Widmer, E. D. (2006). Who are my family members? Bridging and binding social capital in family configurations. *Journal of Social and Personal Relationships*, *23*(6), 993–1012. https://doi.org/10.1177/0265407506070482

Widmer, E. D. (2007). Social capital in wide family contexts: An empirical assessment using social network methods. *International Review of Sociology*, *17*(2), 225–238. https://doi.org/10.1080/03906700701356861

Widmer, E. D. (2016). *Family configurations: A structural approach to family diversity*. Abingdon, UK: Routledge.

Widmer, E. D., Aeby, G., & Sapin, M. (2013). Collecting family network data. *International Review of Sociology*, *23*(1), 27–46. https://doi.org/10.1080/03906701.2013.771049

Widmer, E. D., Kempf, N., Sapin, M., & Galli-Carminati, G. (2013). Family beyond parents? An exploration of family configurations and psychological adjustment in you adults with intellectual disability. *Research in Developmental Disabilities*, *34*, 207–2017. https://doi.org/10.1016/j.ridd.2012.07.006

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*, 176–187. https://doi.org/10.1016/j.ridd.2007.02.005