

Chapter 5

Informal support for parents with mild intellectual disabilities: Factors associated with differences in amount of support

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Abstract

In the field of child and social welfare, the concept of empowering families and their informal networks to address their social problems has been emerging. The informal support that parents with MID (mild intellectual disabilities or borderline intellectual functioning) receive, appears open for improvement. To be able to assess the potential of network-oriented social work for parents with MID, insight is needed in factors associated with the extent to which informal network members can offer support. Network members of parents with MID (N = 117) reported on the amount of support they provided and possible determinants of their support. These data were combined with parental reports (N = 33). Mothers and sisters appeared to provide more support than partners of parents with MID. Mothers reported providing more child-rearing specific support than sisters. Mothers reported providing more support if they lived further away from the parent, if parents felt less comfortable to ask for support, and if relationship quality was low. Sisters reported more provided support if parents waited less long to ask for support. These findings, while exploratory, indicate that for different network members (e.g., partners, mothers, sisters) different factors might impede or promote the support they provide to parents with MID. Implications for research and practice are discussed.

Introduction

Parenting is a complex task that is seldom carried out in isolation. Just as other parents, parents with mild intellectual disabilities (MID) or borderline intellectual functioning (BIF; in this article further referred to as parents with MID) may at one point or another need support to some degree with raising their children. While insight has been gained in the role that professional support may play (Meppelder, Hodes, Kef, & Schuengel, 2014; Coren, Thomae, & Hutchfield, 2011; Llewellyn & McConnell, 2002), the potential role of natural support networks has received less attention. In the field of child and social welfare, the concept of empowering families and their informal networks to address their social problems has been emerging since the proliferation of family group conferences (Marsh & Crow, 1998), Signs of Safety (Turnell & Edwards, 1999), and other innovations that are aimed to make coercive welfare practices by professional services obsolete. To be able to assess the potential of network-oriented social work for parents with MID, insight is needed in factors associated with the extent to which informal network members can offer support.

Social support is an important contributor to well-being of people (Uchino, Cacioppo, & Kiecolt-Glaser, 1996). Social support is of direct influence on people's physical and psychological health, and can buffer against the negative impact of stressors on people's quality of life. Social support has also been linked to parenting quality and to factors that are associated with parenting quality. Low social support has been linked to less maternal warmth and responsiveness (Burchinal, Follmer, & Bryant, 1996), and to higher psychiatric symptoms (McConnell, Mayes, & Llewellyn, 2008) and higher parenting stress as related to child behaviour problems (McConnell, Breitreuz, & Savage, 2011). These positive effects of social support on parenting are also likely to apply to parents with MID (Aunos & Feldman, 2002).

In their review of studies that focused on social support and well-being among parents with MID, Darbyshire and Kroese (2012) observed a positive association between social support and parental well-being. The idea that social support played a causal role in improving well-being was supported by their finding that interventions to improve social support also improved parental well-being. Furthermore, they concluded that there was an association between satisfaction with social support and positive maternal reactions in parenting situations, indicating that social support might positively impact parenting. In a quick scan study among organisations and staff supporting parents with MID on factors associated with parenting quality in families in which parents have MID, staff identified strong social support networks as one of the most important factors contributing to good enough parenting quality (Willems, De Vries, Isarin, & Reinders, 2007).

While social support has been identified as a factor positively affecting lives of parents with MID, the informal support that parents with MID receive appears open for improvement. Descriptive studies about support networks of parents with MID showed that informal networks were small (Llewellyn & McConnell, 2002), and not in proportion to the large number of formal support figures that networks comprised. Parents mostly relied on family members and had few or no friends, neighbours or other social network members to fall back on. In addition to limitations in quantity of support, there might be problems in the quality of support. Parents with MID face negative attitudes of others towards them being a parent (Aunos & Feldman, 2002). Furthermore, parents and informal network members do not appear to agree on the amount of support that parents need and on the domains that parents need support in (Llewellyn, McConnell, & Bye, 1998). At the same time, studies have shown variation in these network characteristics. Some informal networks managed to offer parents with MID the support they needed, while others did not. Little is known about factors explaining this within group variation.

Part of the variance in support that informal network members give, might be explained by factors related to the network itself. Geographical distance to the family might be a limiting factor. In a study among 70 parents with MID, parents had less frequent in-person contact and more frequent phone contact with network members who lived further away from the parent (Llewellyn & McConnell, 2002). But also the extent to which network members hold concerns about the family where one or both parents have MID might play a role in the amount of support they offer. If network members are worried about the quality of parenting or the safety of the children, they may be more inclined to support the family.

In addition, the quality of the relationship between parents and their informal network members might play a role in the amount of support that network members offer. Parents with MID often have had a problematic child-rearing. A substantial part of the parents with MID have experienced abuse and neglect themselves (Granqvist, Forslund, Fransson, Springer, & Lindberg, 2014; McGaw, Shaw, & Beckley, 2007). A troubled relationship history may contribute to the development of distrust and avoidance in current relationships. When relationships between parents with MID and their informal network members continue to be troubled, offering and accepting social support between family members may be problematic (Merz, Consedine, Schulze, & Schuengel, 2009).

Finally, parents with MID themselves vary in their tendency to turn to network members for support. This might be a consequence of the factors as described above, such as a better relationship with, or limited geographical distance to a network member. However, there might also be parental factors that contribute to parental

support seeking tendency. Parental appraisal of one's own resources to address challenges associated with child-rearing has been shown to be associated with support seeking tendency. Parents who felt more challenged by their role as a parent turned to professional support sooner (Meppelder et al., 2014).

The evidence thus far on support for parents with MID from informal network members has mostly been done from parental perspectives and not yet from the perspectives of network members themselves. The relatively few studies that included network members have focused on network members as one group, and no attention has been given to possible differences among network members. Informal network members might differ in their views with regard to their supporting role and towards a parent with MID, depending on their position within the network. For example, the own mothers of parents with MID might hold different views than partners of parents with MID, because of differences in the duration of the relationships (lifelong vs. shorter relation), difference in direct consequences and opportunities to experience difficulties or offer support, or because of intergenerational factors associated with parenting and MID.

The overall aim of the current study was to explore the perceptions and experiences of network members of parents with MID regarding support to the parent. The specific objectives were to describe the positions (e.g. mothers, fathers, friends) of network members that were identified as potential support figures. Then, network members were grouped based on their position in the network. For each position group, amount, and type (general or child-rearing specific support) of support were described and differences between groups were explored. Finally, associations between the amount of support offered by network members and possible determinants related to the network member, parent, or relationship were explored.

Geographical distance between network members and parents, and network members' concern about parents and children were included as network member characteristics. Furthermore, relationship quality was included as an interpersonal factor associated with the amount of support offered. With regard to the parent, general parental latency, that is the time parents waited to ask informal support in difficult child rearing situations was examined as an associated factor. Also parental comfort to ask and accept support was included as a factor associated with informal support.

Methods

Procedure

Participants for the current study were recruited via parents that participated in a study on support seeking among parents with MID (Meppelder et al., 2014). During a home visit, parents were asked to identify network members that could be approached for a study on factors impeding or facilitating supporting a parent with MID. Network members were informed about the study by phone and information letters, and informed consent was obtained by letter.

Data from network members were obtained by a questionnaire, which focused on issues that were identified in a qualitative study among fourteen network members of parents with MID. Focus groups and individual interviews resulted in a list of factors associated with providing informal support for parents with MID (De Kimpe & Nieuwenhuis, 2012). Language of the questionnaire was made accessible, because literacy was expected to vary strongly for network members of parents with MID. To prevent confusion between the “parents” with MID as subjects of the questions and the own “parents” of the network members, the name of the parent was used instead of the term “the parent” (e.g., “How often do you support Mary?” instead of “How often do you support the parent?”). To do justice to the large number of topics that were put forward in the focus group while preventing overburdening the participants, several highly concrete constructs were operationalized with small numbers of items, or single items in this exploratory survey. Questionnaires were mailed-out with a cover letter and a return postage paid envelope. Network members were reminded by letter and by telephone to fill out the questionnaire. Network members received a gift voucher of 7.50 euro for participation. The questionnaire was sent to 170 network members of 47 parents with MID. One hundred seventeen network members returned the questionnaire.

Parents were interviewed about their experiences with asking and accepting informal support with an extended version of the Support Interview Guide (SIG; Llewellyn & McConnell, 1999). Parents participated in the SIG as a part of a larger data collection during a 2-hour home visit. All parent respondents received a gift voucher of 25 euros. For an extensive description of the procedure for parents, see Meppelder et al. (2014).

Ethical approval was obtained by the Medical Ethical Committee of VU University Medical Centre, Amsterdam (ref.nr. NL31934.029.10).

Participants

The network members that returned the questionnaire had the positions of partners, fathers, mothers, sisters, other family members, friends and neighbours (see Table 1). Eleven network members were grouped as “other”. Data from mothers (N = 22), partners (N = 15) and sisters (N = 15) were subjected to statistical analysis. Other categories were excluded for further analyses because of too large variety within the group of network members (family members, others), or too small sample sizes for analyses (friends, fathers, neighbours and brothers) to be meaningful. Demographic data for mothers, partners and sisters are depicted in Table 2.

Table 1. Frequencies for groups of network members based on position of the network member within the informal network

Network member	Frequency	%
Family members	25	21
Mothers	24	20
Partners	15	13
Sisters	15	13
Friends	13	11
Fathers	10	9
Neighbours	3	3
Brother	1	1
Others	11	9
Total	117	100

Table 2. Demographics for network members and parents with MID

	Mothers (n = 24)	Partners (n = 15)	Sisters (n = 15)	Parents (n = 33)
Age (year ; month)	55 ; 9	37 ; 4	34 ; 4	29 ; 9
Ethnicity				
Dutch	17	12	13	25
Other	7	3	2	6
Education level *				
Primary	9	3	1	3
Lower secondary	10	6	5	18
Higher secondary	5	6	9	7
Employment status				
Paid work	14	10	7	7
Volunteer	1	1	1	4
No work	9	4	7	19

* Following the International Standard Classification of Education of UNESCO

In order to study the associations between on the one hand the network member responses and on the other hand the responses of parents with MID, 33 parents whose network members participated were included in the analysis. Demographic data for parents are depicted in Table 2. All parents were female and all partners were male.

Measures

Amount of informal support

The amount of support that network members provided to the parent with MID was assessed using three sets of items: general support (6 items: household, administration, practical support, emotional support, personal life of the parent and childcare), advice on child-rearing in general (1 item) and specific aspects of support on child-rearing (7 items: spending time with children, nurturing, playing, school, discipline, rules, adjusting to age). Items were partially based on the Support Interview Guide (SIG; Llewellyn & McConnell, 1999). Respondents were asked to answer on a 3-point scale (1 = “more than once in three months”, 2 = “once in three months”, 3 = “not”). Answers were recoded so that higher scores indicated more support. Cronbach’s alpha’s were 0.75 for general support and 0.93 for the 7 items on specific aspects of support on child rearing.

Distance

A question on distance between the network member and the parent was taken from the Support Interview Guide (Llewellyn & McConnell, 1999). Network members reported on the distance between them and the parent on a 6-point likert-scale (1 = In same house, 2 = In same street, 3 = In same neighbourhood, 4 = In same town, 5 = In same province, 6 = Further away).

Concern

Eight questions on the level of concern of social network members were based on the Involvement Evaluation Questionnaire (BES; Schene & Wijngaarden, 1992). The questions were answered on a scale ranging from 1 ((almost) always concerned) to 5 (never concerned). The reliability of the eight concern items was satisfactory (Cronbach’s alpha 0.86). Answers were recoded so that higher scores represented higher levels of concern.

Parental comfortableness in asking and accepting support

The Support Interview Guide (Llewellyn & McConnell, 1999) was developed for research with parents with MID, and focuses on support network composition and characteristics of the network members and relationships between the parent and each of the network members (Llewellyn & McConnell, 2002). The SIG uses simplified language, coloured response cards and graphics to illustrate support concepts and to visualize response scales. In the SIG, parents are asked to indicate how comfortable they feel to ask support and to accept support from each of their network members, on a scale from 1 (not comfortable) to 4 (very comfortable). The mean score of the parents' answers on comfort in asking (1) and comfort in accepting (2) support was used for the current study.

These two questions on parental comfort to ask and accept support were adapted for use with network members ("How comfortable does Mary feel to ask/accept support from you?") and presented to network members in the questionnaire. The mean score of the network members' answers on comfort in asking (1) and comfort in accepting (2) support was used as a second indicator of parental comfort in asking and accepting support.

Parental latency to ask informal support

To assess parental support seeking in the context of child rearing, the SIG (Llewellyn & McConnell, 1999) was expanded with two hypothetical difficult child rearing situations (vignettes). Each vignette was followed by semi-structured interview questions. Parents were asked to indicate "Who would/did you ask for support?" and "When would/did you contact this person?" (directly or the next day, after a few days, after a week or longer). Scores for informal support seeking were based on parental latency to ask for informal support, which is the time parents waited to ask for support with an informal support network member. Asking for informal support directly or the next day was scored as 1, after a few days was scored as 2, after a week or longer was scored as 3, and no support asked was scored as 4. A mean score was computed for parental reactions on the vignettes and the real-life situations separately (for a detailed description, see Meppelder et al., 2014). Higher scores on the outcome variable, latency, represented a longer waiting time to ask for support.

Data analysis

The data were analysed using IBM SPSS statistics version 20. Differences between groups of network members on the amount of support they provided to the parent were tested with independent samples t-tests, given that only in a majority of cases the different network members (mothers, sisters, and partners) belonged to the

same network. Associations between amount of support as provided by each group of network members and other study variables were tested using the nonparametric Spearman correlation coefficient, because of the small sample sizes. Because of the exploratory nature of the study and the small sample sizes, a confidence interval of .90 was used and results were marked as significant if the p-value was smaller than .10.

Results

Differences between groups of network members

Table 3 presents descriptive statistics for the variables as reported by the network members, for mothers, partners and sisters. To test whether differences in support provided by mothers, partners and sisters were significant, independent samples t-tests were performed. On general support, the difference between mothers and partners was significant, $t(37) = 3.67$, $p = .001$, indicating that mothers reported more provided general support than partners. In addition, the difference between partners and sisters was significant, $t(28) = 5.55$, $p < .001$, indicating that sisters reported more provided general support than partners. On general child-rearing support, the difference between mothers and sisters was significant, $t(37) = 1.78$, $p = .08$, indicating that mothers reported more provided child rearing support than sisters.

Amount of support and associations with other study variables

Tables 4 to 6 show associations between support provided by network members and other study variables. The group of parents that was included in analyses differed as a consequence of the fact that these associations were split up for three subgroups of network members (mothers, partners and sisters).

Mothers

Table 4 presents Spearman's correlation coefficients for all study variables for the parent-mother dyads. Results show that the amount of general support of the mothers was positively associated with geographical distance ($r_s = .39$, $p = .06$), indicating that mothers offered more support when they lived at a larger distance from the parent. Child-rearing-specific support was negatively associated with parental comfort to ask and accept support ($r_s = -.44$, $p = .04$), meaning that mothers offered more child-rearing-specific support when parents appeared more inhibited to ask and accept support. Child-rearing-specific support was negatively associated with relationship

Table 3. Descriptive statistics on study variables as reported by network members for mothers, partners and sisters of parents with MID

	Range	Mothers		Partners		Sisters	
		Mean	SD	Mean	SD	Mean	SD
General support	1 – 3 ^a	1.99	.50	1.44	.35	2.24	.43
Child rearing support							
General	1 – 3 ^a	2.17	.70	2.00	.93	1.73	.80
Specific	1 – 3 ^a	1.68	.58	1.80	.84	1.43	.69
Distance	1 – 6 ^b	4.83	1.09	2.00	2.07	4.60	1.35
Concern	1 – 5 ^c	2.60	.54	2.70	.91	2.63	.77
Relationship quality	1 – 4 ^d	3.17	.76	3.20	.78	2.73	.88
Parental comfort asking and accepting support	1 – 4 ^e	2.42	.75	3.03	.65	2.13	.75

^a 1 = Not, 2 = Once in past 3 months, 3 = More than once in past 3 months ^b 1 = In same house, 2 = In same street, 3 = In same neighbourhood, 4 = In same town, 5 = In same province, 6 = Further away ^c 1 = Never, 2 = Sometimes, 3 = Regularly, 4 = Often, 5 = (Almost) always ^d 1 = Not good, 2 = Reasonable, 3 = Good, 4 = Very good ^e 1 = Not comfortable, 2 = A little comfortable, 3 = Comfortable, 4 = Very comfortable

Table 4. Spearman’s correlation coefficients of *parent-mother dyads* (N=24) for all study variables

	General support	Child-rearing specific support	Distance	Concern	Relationship quality	Parental comfort asking and accepting support	Latency informal support seeking
	General Aspects				Mother Parent		
General support	-						
Child-rearing specific support							
General	-.13	-					
Aspects	-.07	.66*	-				
Distance	.39*	-.12	-.30	-			
Concern	-.08	.34	.30	-.11	-		
Relationship quality	-.06	-.37*	-.34	.36 [†]	-.45*	-	
Parental comfort asking and accepting support							
Mother	-.04	.15	-.01	-.02	.11	.16	-
Parent	.28	-.44*	-.55*	.21	-.19	.36*	.34
Latency informal support seeking	.08	.12	-.07	.06	.34	-.23	-.22
							.07
							-



Table 5. Spearman's correlation coefficients of *parent-partner dyads* (N=15) for all study variables

	General support	Child-rearing specific support	Distance	Concern	Relationship quality	Parental comfort asking and accepting support	Latency informal support seeking
	General Aspects					Partner	Parent
General support	-						
Child-rearing specific support							
General	-.66*	-					
Aspects	-.52	.85*	-				
Distance	.00	.00	-.06	-			
Concern	-.39	.34	.33	.25	-		
Relationship quality	-.12	.08	-.09	-.37	-.12	-	
Parental comfort asking and accepting support							
Mother	-.05	.04	.05	.27	.17	.26	-
Parent	.13	.22	-.07	.12	-.10	.27	.37
Latency informal support seeking	-.02	.29	.16	.08	.14	-.23	-.39

Table 6. Spearman's correlation coefficients of *parent-sister dyads* (N=15) for all study variables

	General support	Child-rearing specific support	Distance	Concern	Relationship quality	Parental comfort asking and accepting support	Latency informal support seeking
	General Aspects					Sister	Parent
General support	-						
Child-rearing specific support							
General	-.26	-					
Aspects	-.31	.88*	-				
Distance	.39	-.37	-.35	-			
Concern	-.24	.40	.46†	.29	-		
Relationship quality	-.22	-.25	-.26	-.06	-.52*	-	
Parental comfort asking and accepting support							
Mother	-.43	.12	.17	-.26	-.33	.86*	-
Parent	.53	-.33	-.27	.15	-.45	-.27	-.44
Latency informal support seeking	.26	-.50*	-.37	.00	-.17	.01	-.11

quality ($r_s = -.37, p = .08$), meaning that mothers offered more support when relationship quality was lower.

There were three other associations between the other study variables that were significant: Relationship quality was positively associated with geographical distance between the mother and the parent ($r_s = .36, p = .08$), meaning that mothers experienced a better relationship with their daughters if they lived at a larger distance from the parent. Furthermore, relationship quality was negatively associated with concern ($r_s = -.39, p = .06$), meaning that mothers reported less concern about their daughters if they experienced a positive relationship with their daughters. Finally, relationship quality was positively associated with parent reported comfort to ask for support ($r_s = .36, p = .096$), indicating that daughters felt more comfortable to ask and accept support from their mothers if mothers experienced a better relationship quality with their daughters.

Partners

For parent-partner dyads, there were no significant associations between amount of support, general or child-rearing-specific, and other study variables (see Table 5). There were no significant associations among the other study variables either.

Sisters

For parent-sister dyads, there were no significant associations between amount of general support offered by sisters and other study variables (see Table 6). Child-rearing-specific support was negatively associated with parental latency to ask for informal support ($r_s = -.50, p = .06$), indicating that sisters offered more child-rearing-specific support if parents waited less to ask for informal support.

Two associations between the other study variables were significant. Sisters showed less concern about the parent and his or her child when they reported higher relationship quality ($r_s = -.54, p = .04$). Furthermore, sisters reported higher relationship quality if they reported higher parental comfort to ask and accept support ($r_s = .86, p < .001$).

Discussion

In this study, the perspective of social network members on the support they provided to a parent with MID was explored. Differences between three subgroups of network members (mothers, partners and sisters) were studied. Finally, possible factors associated with the support that network members offered to parents with MID

were explored. Two types of support were distinguished: general support, focusing on practical or emotional aspects of the parents' life, and child-rearing specific support. Practical, network member, parental and relationship specific factors were studied as being possibly associated to support.

The results on differences between support provided by mothers, sisters and partners indicated that mothers might be the most important sources of support for parents with MID. Mothers offered more general support, including practical and emotional support, than partners. In addition, mothers reported higher levels of provided child-rearing support than sisters. Providing multiple types of support has been known as multiplexity (Llewellyn & McConnell, 2002), and has been shown to be positively associated with closeness and a longer duration of the relationship. Mothers might not always be closest to their daughters, yet often they are the support figures with the longest relationships with parents with MID.

Unexpectedly, mothers of a parent with MID did not offer more support when the hypothesized barriers for support were low. In contrast, mothers appeared to offer more child-rearing specific support when parents reported less comfort to ask and accept support from them. Furthermore, mothers reported that they offered more child-rearing support when relationship quality was lower and more general support when the geographic distance to the parent was larger. Although the exploratory nature of the study must be taken into account, these results appear to be contra-intuitive. Reflecting on these findings, it might be that mothers adequately interpret a low relationship quality and low parental comfort to ask and accept support as risk factors for support seeking (Meppelder et al., 2014). Mothers might then take a pro-active approach in providing support to their daughter. This explanation was supported by the fact that mothers were more concerned when relationship quality was low. Furthermore, compared to general support, support with child rearing may be an area that may be experienced as sensitive or intrusive. If for any particular reason mothers of parents with MID, in their role of grandparent, deem it necessary to provide support with child rearing, this may contribute to conflict with their daughters who attempt to cope with parenting independently.

With the explorative analyses in the current study, no factors could be identified that were associated with support as given by partners. There appear to be two contrasting types of relationships among parents with MID and their partners. In a group of 54 mothers with MID, Booth and Booth (2002) categorized 30 partners as supportive and 24 partners as exploitative or abusive. If these findings apply to the sample of the current study, more complex assessment of perceptions and motives of partners may have been needed.

The support that sisters provided to a parent with MID appeared to depend, more than support of mothers, on parental signals. The amount of child-rearing support that sisters provided was higher when parents asked for support earlier. Sisters might feel less responsible for children's wellbeing than mothers, who in their role of grandparents may feel entitled to go against parental signals in the interests of the child. This corresponds with the finding that mothers reported more involvement with child rearing support than sisters. Furthermore, the relationship between sisters might be more equal than the relationship between mothers and children with MID. The classic division of roles in a family, with the mother being responsible and the child being dependent, might again come up or continues to be present, when children start their own families.

Limitations

Results of the current study must be interpreted within the context of its limitations. First, the current results were based on small sample sizes, ranging from 24 to 15. With this small samples, associations between informal support and possible predictors could be explored. Further research is needed to test the topics of the current study in larger samples. In addition, the current study was primarily based on self-reports of network members. Little is known about whether reports of network members would agree with parental reports on the variables of the current study (e.g., amount of support provided or relationship quality). The sometimes unexpected findings may be reflective of complex family dynamics that require more finegrained, comprehensive, and qualitative analysis.

Finally, the selection of participants of the current study might have resulted in a bias of the findings. Parents were selected from a larger sample, after which parents selected network members from their support networks. Then, network members selected themselves by consenting for the survey-study and sending back the questionnaire. The group of network members and parents that remained in the study, might differ strongly from network members that were not included and this selection bias limits the generalizability of the current findings.

Implications

Notwithstanding the exploratory character of the study, the current results have implications for further research and for practice. Further research on informal support for parents with MID should aim to enrich the current quantitative findings with qualitative data on factors associated with providing support to a parent with MID. Possible explanations for the current findings, in particular on provided support by mothers against signals indicating possible risk for parents, could then be studied

more in depth. An important direction to take is to study how relationships between parents with MID and their network members evolve over time and affect and are affected by the support exchanged, desired and undesired (Merz, Schulze, & Schuengel, 2010).

Furthermore, the current study highlighted that there might be differences between network members in the perception of their role as a support figure for parents with MID. Sisters appeared to attune their support more to parental signals of accessibility for support, while mothers appeared to react to signals of risk of their children with MID. Future research might be able to adjust research designs to explore these possible differences more in depth.

The current study appears to show a pattern of results underlining the importance of relationship quality for informal support. Sisters and, to a lesser extent, mothers appeared to be less concerned when relationship quality was high. Furthermore, parents appeared to be more comfortable to ask and accept support from their mother and sisters when relationship quality was good. In a time frame of empowering vulnerable persons by empowering their families and broader informal networks, an implication of the current study for clinical practice could therefore be to focus on improving relationship quality of parents with MID and their informal network members. This might contribute to a strengthened connection between informal support and parents with MID.

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Chapter 5

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