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Research in Developmental Disabilities



1

Highlights

Family beyond parents? An exploration of family configurations and psychological adjustment in young adults with intellectual disabilities

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► Family support to individuals with ID goes beyond parental support. ► Family configurations of individuals with ID include care professionals in many cases. ► Structural features of family support to persons with ID matter. ► Family configurations of these individuals correlate with their psychological adjustment.

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2 Family beyond parents? An exploration of family configurations and 3 psychological adjustment in young adults with intellectual disabilities

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ABSTRACT

This research explores the family configurations of young adults with intellectual disability. Based on a sample of 40 individuals interviewed two times in a year, we found as many as four types of family configurations, with distinct compositions, and different types of social capital. This diversity is not without consequences for individual psychological adjustment. The results are discussed in the light of the configurational approach to families.

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9

10 1. Introduction

11 Family members are centrally important in psychological health, as the family is a primary resource of care and support
12 (Fehr & Perlman, 1985; Furstenberg & Kaplan, 2004a, 2004b; Widmer, 2004). Despite the substantial attention given to
13 family support for individuals with intellectual disabilities (ID), the diversity of such support was seldom taken into account
14 empirically. Indeed, most studies focus on help from the nuclear family, especially from parents (Heiman & Berger, 2008),
15 and do not consider the wider social and family contexts and their structural properties (Emerson et al., 2010; Faber &
16 Wasserman, 2002). As family contexts have become more heterogeneous and open in recent decades due to the pluralization
17 of life courses (Kohli, 2007; Shanahan, 2000), the focus on parents as single sources of support for adolescents and young
18 adults with intellectual disabilities should be reconsidered. This contribution stresses the importance of including larger
19 configurations of family ties when dealing with the interrelation between family support and the psychological adjustment
20 of individuals with intellectual disabilities. It stresses that young adults with ID are embedded in various family
21 configurations, which provide them with distinct types of social capital and which have consequences for their psychological
22 adjustment.

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23 2. Literature review

24 2.1. Family support and psychological adjustment

25 A large body of literature in epidemiology and community psychology shows that family support positively affects
26 psychological adjustment (Berkman, Glass, Brisette, & Seeman, 2000; Kawachi & Berkman, 2001). Closeness with mother
27 and father is associated with higher psychological adjustment (Rothon, Goodwin, & Stansfeld, 2012). Overall, cohesive
28 and supportive families have a beneficial effect on psychological adjustment of adolescents and young adults (Timko &
29 Moos, 1996). However, parental support was found functionally distinct from that provided by siblings or friends, who
30 usually provide some form of companionship (Berrera, Chassin, & Rogosch, 1993). Indeed, family roles insure a diversity
31 of helps. Close family members provide a wide range of resources, while individuals who are less close provide either
32 emotional support or services but generally not both (Agneessens, Waeye, & Lievens, 2006; Wellman & Worthley, 1989,
33 1990). Indeed, close kin hold a central position in providing social support and differ from friendship in both the amount
34 and quality of support. Individuals—most often parents, siblings, and adult children—who provide instrumental help tend
35 to offer emotional support also. However, for some individuals, extended kin also play a key supportive role (Agneessens
36 et al., 2006).

37 Regarding psychological adjustment, it must be mentioned that all types of support have not been considered as equally
38 important, as perceived emotional support holds a prominent place (Lin & Peek, 1999). Among the few studies approaching
39 social support as a property of an extended family exchange system (for a review, Ferguson, 2006), high levels of support
40 from a variety of family members reduce the likelihood that children experience depressive symptoms (Stevenson, 1998).

41 These results suggest that social support provided by parents to adolescents and young adults is embedded in broader
42 networks of relationships, which structures matter (Faber & Wasserman, 2002). Several studies found that large networks
43 were associated with higher psychological adjustment, while others found no difference or negative correlations between
44 network size and psychological adjustment (Lin & Peek, 1999; Moren-Cross & Lin, 2006; Song, Son, & Lin, 2011). Adolescent
45 and young adults well connected in peer networks present less depressive symptoms (Okamoto et al., 2011; Ueno, 2005).
46 Studying friendship networks of adolescents, Ueno (2005) also showed that the relationship between having more friends
47 and fewer depressive symptoms was largely mediated by a sense of belonging. Falci and McNeely (2009) highlighted a
48 curvilinear effect of network size on depressive symptoms. Having only one friend is significantly found to be associated with
49 depressive symptoms, but over-integration with too many friends also leads to higher depressive symptoms. These authors
50 hypothesize that too many friend might be too demanding, but they also found that the negative effect of larger networks
51 depends of the network density. It was hypothesized that dense configurations of ties, in which there are many connections
52 between network members, protect individuals facing stressful events by providing more social support. Studies dealing
53 with structural dimensions of support beyond the parental or the conjugal dyads are however scarce and provide mixed
54 evidence (Lin & Peek, 1999). Falci and McNeely (2009) found nevertheless that highly dense networks protect against
55 depressive symptoms among adolescent girls embedded in large network of friends. Very few studies, however, deal with
56 the centrality of individuals in their personal networks. One (Cornwell, 2009) found that individuals with poor physical and
57 mental health less often hold a intermediary position in their network, a situation which might well be too demanding for
58 vulnerable individuals.

59 2.2. Family configurations and intellectual impairment

60 There is even less research on family support provided to individuals with ID and its consequences for their own
61 psychological adjustment. During several decades, research has focused on how individuals with ID negatively affect their
62 parents and siblings. Families of individuals with ID were thought to experience adverse costs consequent from over care.
63 People with ID were considered as imposing high social and emotional costs and as being a source of stress (Eisenhower,
64 Baker, & Blacher, 2009; Hatton et al., 2010; Hastings, 2002; Haveman, Van Berkum, & Reijnders Heller, 1997; Martorell,
65 Gutiérrez-Recacha, Irazàbal, Marsa, & García, 2011). On another hand, some authors underline the risk to overestimate the
66 link between intellectual disability and parental well-being due to unaccounted socioeconomic factors (Emerson et al.,
67 2010). Indeed, families taking care of a child with ID are significantly more likely to be exposed to socioeconomic
68 disadvantages (Emerson & Hatton, 2008). Therefore, the burden of raising a child with ID may have been overemphasized
69 (Hodapp & Dykens, 2009), as many family members also report life-enhancing benefits from raising a child with ID (Blacher
70 & Baker, 2007; Green, 2007; Stainton & Besser, 1998; Taunt & Hastings, 2002).

71 Research focusing on individuals with ID suggests that they have fewer supportive relationships (Rosen & Burchard,
72 1990). Globally, adults with ID receive less emotional support and companionship from family members and friends than
73 individuals without ID (Rosen & Burchard, 1990) and more support from care professionals (Forrester-Jones et al., 2006;
74 Lunsky & Benson, 1999). Regarding psychological adjustment, one of the main studies dealing with the influence of social
75 support in the context of ID showed that supportive social networks are associated with personal and family well-being
76 (Dunst, Trivette, & Cross, 1986). More supportive social networks trigger a higher level of personal well-being. Relationships
77 with friends who also had intellectual disabilities appeared to be protective against feeling helpless. Some differences
78 between men and women have also been observed, as for women, being single was associated with greater well-being
79 (Emerson & Hatton, 2008).

Hastings (2002) also stressed that support has distinct effects on well-being, depending on the personal characteristics of the person with ID, as well as on the kind of care and the services available. In a longitudinal perspective, a connection was shown between changes in social support and the psychological well-being of mothers of adults with ID (Hong, Seltzer, & Krauss, 2001). Similarly, it was found that mothers of children with ID who present a lack of well-being tend to seek for additional emotional and social support (Benzies et al., 2009). In a study examining perceived social support over time in a sample of adults with mild retardation, there was a beneficial influence of positive relationships on psychological adjustment (Lunsky, 2001).

Overall, these results suggest that research should pay more attention to support provided to individuals with ID by a variety of family members, not only parents. A larger set of family ties, beyond the nuclear family, should be taken into account when addressing the impact of family support on psychological adjustment of individuals with ID.

2.3. Family resources as social capital

Individuals with ID may have unequal access to key relational resources within their families. Several researchers have conceptualized personal ties as social capital, i.e., relational resources embedded in a social network that are mobilized in purposive actions (Lin, 2001; Song, 2011). Family social capital was hypothesized to have various positive consequences for individuals, such as promoting physical and psychological health or increasing individual resilience against non-normative events in the life course (Furstenberg & Kaplan, 2004a; Widmer, 2006). Three types of social capital have been distinguished by research (Szreter & Woolcock, 2004). Bonding social capital features network closure—that is, redundancy of ties within a group characterized by a high density of relationships. In dense networks, most if not all individuals are interconnected, a situation that enhances expectations, claims, obligations, and trust among them. Therefore, support has a collective nature in dense networks, as several individuals are likely to coordinate their efforts when helping another. Bridging social capital (Burt, 2004) describes social capital as a function of brokerage opportunities: the weaker connections between subgroups of a network create “holes” in the structure that provide some persons, brokers, with opportunities to mediate the flow of information between group members. Some families, especially those associated with divorce and remarriage, provide a higher level of such social capital and less bonding social capital (Widmer, 2010). Linking social capital was proposed as an alternative pertaining to connections that individuals develop toward institutions (Song, 2011; Szreter & Woolcock, 2004). By extension, we refer linking social capital to officials and care professionals who represent institutions and who are, therefore, key intermediaries for obtaining the resources that these institutions offer to individuals with ID.

Research stressed that individuals with ID have small personal networks and a lack of social capital (Forrester-Jones et al., 2006; Krauss, Seltzer, & Goodman, 1992; Robertson et al., 2001; Widmer, Kempf, Lanzi, Robert-Tissot, & Galli-Carminati, 2008). It is also true for family ties: individuals with ID have on average smaller and less connected family configurations compared with individuals from the general population (Cummins & Lau, 2004; Widmer, 2007; Widmer & Galli-Carminati, 2006; Widmer et al., 2008). Their family configurations include fewer partners, parents and siblings considered as significant by respondents, as well as a smaller set of such relatives as grandparents, uncles and aunts, or cousins.

This strain on family ties for individuals with intellectual disabilities should not, however, be considered as evidence that individuals with ID are generally isolated from family members. Individuals with ID have not been exempt from the great changes associated with the destandardization of life trajectories and the pluralization of families, which have happened since the 1960s in most Western countries (Kohli, 2007; Shanahan, 2000). Therefore, their significant family contexts might be diverse, branching out in various directions, on either their mother's or father's side, including friends considered as family members, step-relatives, and possibly in-laws or even care professionals, with likely consequences for their social capital and their psychological adjustment (Widmer, 2010).

2.4. Summary

Little is known about the family configurations of individuals with intellectual impairment and the relational resources that they provide, especially when their recollections are given prominence over the recollections of their family members. This article explores the way in which individuals with ID define their family contexts, as well as the social capital that these contexts provide, according to them. It uses social network methods (Wasserman & Faust, 1994; Widmer, 1999) and it hypothesizes that individuals with ID develop a variety of family configurations, with distinct sizes and compositions, resulting in the availability of unequal levels of social capital. Individuals who are missing one or both parents in their family configurations are less likely to develop bonding social capital (Widmer, 2010). Therefore, we expect that they will develop lower psychological adjustment. However, family configurations that have alternative family ties, such as those with friends and care professionals considered as family members, provide a bridging or linking type of social capital, which may compensate for the lack of bonding social capital in their psychological adjustment.

3. Materials and methods

3.1. Procedures

The data were collected within the frame of an exploratory study of family configurations, intellectual disabilities and mental health (Widmer et al., 2008). In order to have access to individuals with ID, we used a purposive sampling strategy

134 (Bernard, 2012) and contacted a public facility of the Geneva's area which provides support and work to young adults with
135 ID. Individuals with mild or moderate ID are enrolled by the facility into occupational or productive workshops as well as in
136 some cases residential settings. Access to the facility is pending on sufficient autonomy in mobility from home to the facility.

137 To recruit participants for the study, the facility's headquarters sent them a letter explaining them the aims of the study
138 and proposing to them to take part to it. The ethics committee of the Department of Psychology of the University of Geneva
139 approved the research after a standard scrutiny procedure, and formal informed consent was obtained from each participant
140 before the onset of the interviews.

141 Face-to-face personal interviews were carried out by a trained psychologist. All interviews were conducted at the work
142 place of each participant at a convenient time. Interviews took between 35 min and 2 h. For two participants, due to
143 concentration difficulties, two meetings were necessary to complete the first interview. A second interview was proposed to
144 all participants one year later with the same procedure.

145 3.2. Participants

146 Participants were selected within the facility's population according to the following criteria: (a) age between 18 and 35;
147 Q2 (b) mild ID according to the ICD criteria (F70) (WHO, 1993). We excluded from the sample people with a marked co-
148 morbidity diagnosis, as well as individuals having been referred for psychiatric assessment and treatment during the last five
149 years. Forty of 79 illegible individuals between 18 and 35 years old (mean age of 27) accepted to participate to the study, and
150 signed a written consent after being carefully explained the purpose of the study and the confidentiality of the information
151 provided. Eighteen were female and 22 male; 29 lived with their parents, 8 in a community residence, and 3 by themselves.
152 Twenty-three participants accepted to be reinterviewed one year later. Out of them, 16 lived with their parents, 5 in a
153 community residence, and 2 by themselves. No respondent changed her type of residence between the two waves.

154 3.3. Instruments

155 The *Family Network Method (FNM)* (Widmer, 1999; Widmer, Chevalier, & Dumas, 2005; Widmer & La Farga, 1999) was
156 used to estimate the family ties of respondents. Stemming from social network methods (Wasserman & Faust, 1994), this
157 instrument proved to be a reliable tool to assess structural dimensions of relationships in large family contexts beyond the
158 nuclear family. Unlike other instruments measuring family support, it does not a priori define the family members to be
159 taken into account and provides detailed information on all relationships among family members defined as significant by
160 respondents. The instrument was used in a variety of settings (Widmer, 2010), including a sample of individuals with ID
161 (Widmer et al., 2008). Its reliability was tested successfully (Monney, 2007; Widmer, 2010).

162 Respondents were first asked to provide a list of persons that they considered as significant family members at the time of
163 the interview. Based on this list of family members provided by each respondent, several questions about emotional support,
164 conflict, and influence were then asked. As in other cognitive network studies (Krackhardt, 1987), respondents estimated not
165 only their own relationships with their family members, but also the relationships existing among all their family members
166 (Widmer, 1999; Widmer et al., 2005; Widmer & La Farga, 1999). This paper focuses on the issue of emotional support, which
167 topic was introduced as follows: "From time to time, most people discuss important personal matters with other people.
168 During routine or minor troubles, who would give emotional support to X?" In this procedure, all individuals included by the
169 respondent in his or her list of family members were considered one by one.

170 The respondents' psychological adjustment was measured using the *Symptom Check-List-90-R* (Derogatis, 1983;
171 Derogatis, Lipman, & Covi, 1973), a multidimensional self-report inventory commonly used by both researchers and
172 clinicians and presenting reliable and valid psychometric properties with the population with ID (Kelleth, Beail, Newman, &
173 Mosley, 1999). The answers to the 90 items in the questionnaire, rated on a 5-point Likert scale (ranging from 0 "not at all" to
174 4 "extremely"), can be combined subsequently in nine dimensions: Somatization, Obsessive-Compulsive, Interpersonal
175 Sensitivity, Depression, Anxiety, Anger-Hostility, Phobic Anxiety, Paranoid Ideation and Psychoticism. In addition, three
176 indices can be computed to provide global measures of overall mental health: The Global Severity Index (GSI), which is a sum
177 of all symptom; the Positive Symptom Total (PST), which indicates the diversity of symptoms while considering only their
178 presence or absence; and the Positive Symptom Distress Index (PSDI), which is the GSI divided by the PST, an index of
179 psychological distress. Three individuals who answered the family network questionnaire were eventually not willing to
180 respond to the SCL-90-R questionnaire. They were excluded from the analysis.

181 3.4. Data analysis

182 We first built types of family configurations based on the family members cited by respondents as significant. In order to
183 find such types, we followed standard procedures in configurational analyses of families (Widmer, 2006, 2010) and ran a
184 factor analysis on the family roles cited by at least five percents of respondents, as well as on a residual category comprising
185 all other terms. Principal components analysis was used to extract the initial factors (Tabachnick & Fidell, 1996). We retained
186 the first seven factors from the factor analysis and performed a varimax rotation. Then, the factor scores were put into a
187 hierarchical cluster analysis (Lebart, Morineau, & Piron, 1997). The cluster analysis was done using the Ward method on
188 correlation distances. The dendrogram, as well as various diagnoses (Milligan & Cooper, 1985) suggests that four clusters fit

189 the data well (Everitt, 1993). Variance analysis and multivariate regressions were used to estimate the impact of family
190 configurations on the indexes of social capital and the SCL 90 R scales. All analyses were done in the statistical package R (R
191 Development Core Team, 2011).

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4. Results

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Table 1 reports the percentages of respondents who cite holders of various family roles as significant family members. Only family roles cited by at least 5% of respondents were considered separately in the factor and cluster analyses, as other roles were merged into a residual category. Mother, father, brother, and sister are cited by a large majority of respondents and come first in terms of rank order (see Table 1). Mother is clearly prominent, father less so. A variety of blood relatives are also present, such as grandparents, uncles, and aunts. Interestingly, those central family roles are complemented in some cases by care professionals who are considered as family members. This category includes psychologists and social workers, as well as psychiatrists, who are in regular contact with respondents. Hence, in some cases, from the perspective of patients, care professionals play a family role. About 10% of respondents also cited friends and godparents as significant family members. The definition of family contexts by individuals with ID goes beyond the criterion of household membership. Other family roles less often cited but representing significant numbers, nevertheless, include grandparents, uncles, and aunts. Note that no respondent included a partner or a spouse as a significant family member, a result in sharp contrast with results found in generalist samples (Widmer, 2006). By these counts, significant family members extend well beyond the household or the nuclear family. Table 2 presents the average number of citations for each term by each of the four clusters from the selected cluster solution, as well as the percentage of respondents included in each cluster. For single-person terms (such as father or mother), this index corresponds to the percentage of respondents citing them. Table 2 presents the average number of citations for each term by cluster as well as the percentage of respondents included in each cluster. For single-person terms (such as father or mother), this index corresponds to the percentage of respondents citing them.

Cluster 1 (*Professional Family Configuration*) includes 13 respondents. It has an average of 3.5 family members. Respondents belonging to this cluster included their father, mother, and siblings less often than did other individuals. However, they compensated for the absence of those roles by including care professionals as family members. This cluster, therefore, has two main features. On one side, the parents are missing; but on the other side, there is a compensation toward care professionals.

Cluster 2 (*Kinship Family Configuration*) includes 18 respondents. It has an average of 10.4 family members. Respondents in this cluster cited members from their kinship network (uncles, aunts, cousins, other family members) much more often than others did. The number of care professionals cited as family members is very limited, and no friends are considered as family members.

Cluster 3 (*Nuclear Family Configuration*) is the largest group, as it includes 25 respondents. It is much smaller than the previous configuration, with an average of 4.4 family members. Respondents belonging to this cluster focused on their parents and siblings as significant family members. Kinship ties as well as care professionals are under-represented in this cluster.

Cluster 4 (*Friendship Family Configuration*) is the smallest group of all, as it includes only 7 respondents. It has an average size of 7 family members and adds friends who are considered as family members to parents and siblings.

Table 1
Distribution of significant family members.

Terms	Perc. citing the term	Perc. all terms	Cumulated perc.
Mother	94	14	14
Father	83	13	27
Brother	73	11	38
Sister	70	11	49
Mother's mother	27	4	53
Mother's sister	24	4	57
Cousin	14	2	59
Mother's father	14	2	61
Care Professionals	13	7	68
Father's father	11	2	70
Male friend	10	2	72
Father's sister	10	2	74
Godmother	10	2	76
Brother's wife	8	1	77
Father's brother	8	1	78
Father's brother's son	8	1	79
Father's mother	8	1	80
Mother's brother	8	1	81
Half-brother	6	1	82
Other terms	43	18	100

Table 2
Q7 Distribution of family terms by family configurations.

Terms (%)	Care professionals (n = 13)	Kinship (n = 16)	Nuclear (n = 24)	Friendship (n = 7)	F-test	Kruskal-Wallis
Mother	0.692	1.000	1.000	1.000	6.9***	16.1**
Father	0.231	1.000	0.960	1.000	35***	39.1***
Brother	0.462	1.278	0.560	0.429	3.4	8.3
Sister	0.385	0.500	1.080	0.429	2.50	8
Mother's mother	0.154	0.556	0.000	0.714	12.6***	24.2***
Mother's sister	0.077	0.667	0.040	0.143	4.4	13.3***
Cousin	0.231	0.333	0.000	0.000	0.70	2.20
Mother's father	0	0.389	0.000	0.286	5.1	13.8***
Father's father	0	0.222	0.000	0.429	5.7	13.9***
Male friend	0	0.000	0.000	0.857	104.9***	52.2***
Father's sister	0	0.167	0.120	0.000	0.80	2.50
Godmother	0.077	0.222	0.000	0.143	2.20	6.10
Brother's wife	0	0.222	0.000	0.143	3.1	8.5
Father's brother	0	0.278	0.000	0.000	1.60	5.00
Father's brother's son	0	0.167	0.080	0.000	0.81	2.20
Father's mother	0	0.278	0.000	0.000	5.4	13.4***
Mother's brother	0	0.111	0.120	0.000	0.80	2.50
Half-brother	0	0.222	0.000	0.000	2.40	7.7
Care professionals	1.231	0.333	0.200	0.429	4.1	9.2
Other terms	0.900	2.400	0.400	0.400	4.5	9.4

* $p < 0.05$
 ** $p < 0.01$
 *** $p < 0.001$
 # $p < 0.10$.

225 The age and sex of the respondents are not significantly related to the types of family configurations. However, the type of
 226 residence has a strong association with family configurations. Respondents who currently live with their parents have a
 227 much higher likelihood to be included in a Nuclear Family Configuration. Respondents who live in a community facility are
 228 more prone to develop a Professional Family Configuration or a Friendship Configuration. Respondents who live by
 229 themselves are overrepresented in the Professional or Nuclear Family clusters; none of them belong to the Friendship or the
 230 Kinship Family Configurations (Chisquare = 17.7, df = 6, $p < 0.01$).

231 Table 3 cross-tabulates various indexes of social capital by configuration types. The lower density of the Kinship and
 232 Professional Family Configurations shows that respondents in these two configurations have less bonding social capital than
 233 those in the two other clusters. Unexpectedly, the indexes related to bridging social capital, such as the betweenness
 234 centrality, are no higher in these clusters than in the other two clusters. Therefore, there is a lack of social capital in such
 235 family configurations.

236 Table 4 presents a series of linear regressions using the various scales of the SCL-90-R instrument on the first interview
 237 point as dependent variables, and the types of family configurations as the independent variable. In order to control for some

Table 3
Q7 Indexes of social capital by family configurations.

	Care professionals (n = 13)	Kinship (n = 16)	Nuclear (n = 24)	Friendship (n = 7)	F-test	Kruskal-Wallis
<i>Respondents as support seekers</i>						
Size	1	1.8	1.4	2.1	1.50	4.50
Density	0	0.3	0.36	0.46	2.20	7.4
Proportion of components	0.69	0.42	0.66	0.48	1.80	5.30
R. betweenness	0.24	0.12	0.18	0.08	0.43	0.79
<i>Respondents as support providers</i>						
Size	0.9	2.2	1.5	2	1.00	7.6
Density	0.01	0.39	0.27	0.18	2.9	6.6
Prop. components	0.2	0.56	0.65	0.68	3.8	10.7
R. betweenness	0.08	0.11	0.2	0.31	1.30	5.60
<i>Full family networks</i>						
Size	4.6	11.1	5.4	7	18.7***	28.6***
Density	0.16	0.14	0.33	0.26	3.9	10.8
Number of components	2.8	3.8	2.2	1.7	3	9.8
Betweenness centralization	7.7	7.9	15.9	14.9	1.1	11.3

* $p < 0.05$
 ** $p < 0.01$
 *** $p < 0.001$
 # $p < 0.10$.

Table 4
 SCL-90-R scores regressed on family configurations: first interview point. Unstandardized coefficients.

	Total	GSI	PSDI	PST	Depression	Interpers. sensitivity	Anxiety	Somatisation	Hostility	Paranoid id.	Psychoticism	Phobic anxiety	Obs-comp
Intercept	35	0.39	1.7 ^{**}	20.21 [#]	0.41	1.46	0.47	0.53	0.51	0.77 [*]	0.43	0.03	0.57
<i>Family config.</i>													
Professional	-6.80	-0.09	0.05	-6.44	-0.28	1.37	-0.11	0.01	-0.52	0.17	-0.04	-0.11	-0.12
Kinship	28.1 [#]	0.28 [#]	0.16	10.26	0.27	5.28 ^{**}	0.29	0.36	-0.04	0.49	0.38 [#]	0.33	0.21
Nuclear	0	0	0	0	0	0	0	0	0	0	0	0	0
Friendship	-	-	-	-	-	-	0.45	-	-0.19	-	-	-	-0.35
<i>Sex</i>													
Male	0	0	0	0	0	0	0	0	0	0	0	0	0
Female	6.20	0.09	0.03	4.73	0.06	1.70	-0.01	-0.01	0.01	-0.17	-0.05	0.22	0.14
<i>Age</i>													
<25	0	0	0	0	0	0	0	0	0	0	0	0	0
≥25	-0.80	-0.02	-0.11	2.34	0.10	-1.14	-0.07	-0.02	0.05	-0.41 [#]	-0.04	0.01	0.09
<i>Residence</i>													
Parental	0	0	0	0	0	0	0	0	0	0	0	0	0
Community	5.50	0.08	-0.05	5.58	0.32	0.51	0.23	0.14	0.18	-0.01	-0.13	0.01	0.15
Own	15.50	0.14	-0.09	12.56	0.34	2.78	0.30	0.24	0.24	0.23	0.04	-0.12	-0.21
R ²	0.13	0.13	0.07	0.14	0.17	0.36	0.13	0.11	0.08	0.23	0.15	0.16	0.09

* $p < 0.05$

** $p < 0.01$

$p < 0.10$

Table 5
 Q9 SCL-90-R scores regressed on family configurations: second interview point. Unstandardized coefficients.

	Total	GSI	PSDI	PST	Depression	Interpers. sensitivity	Anxiety	Somatisation	Hostility	Paranoid id.	Psychoticism	Phobic anxiety	Obs-comp
Intercept	-16.98	-0.18	1.15 _i	-0.64	-0.26	1.63 _#	-0.78 _#	0.13	0.36	-0.23	-0.22	-0.40	-0.36
<i>Family config.</i>													
Professional	32.53	0.36	0.63 _#	10.96	0.69 _i	0.74	0.18	0.07	0.63	0.70	0.22	0.26	0.23
Kinship	53.31 _i	0.59 _i	-0.11	37.81 _i	0.67 _i	-0.43	1.02 _i	-0.07	0.20	1.06	0.71 _i	0.60	1.02 _i
Nuclear	0	0	0	0	0	0	0	0	0	0	0	0	0
Friendship	-5.39	-0.06	0.46 _#	-5.05	-0.15	0.28	0.04	0.07	0.06	0.14	-0.11	-0.17	-0.01
<i>Sex</i>													
Male	0	0	0	0	0	0	0	0	0	0	0	0	0
Female	32.17 _i	0.35 _i	0.32	13.32 _#	0.44 _i	-0.70	0.66 _i	0.15	0.11	0.33	0.21	0.51 _#	0.39 _i
<i>Age</i>													
<25	0	0	0	0	0	0	0	0	0	0	0	0	0
>25	22.09	0.25	-0.13	10.30	0.25 _#	0.06	0.50 _i	0.37 _#	0.02	0.04	0.21	0.13	0.53 _i
<i>Residence</i>													
Parental	0	0	0	0	0	0	0	0	0	0	0	0	0
Community	-12.64	-0.14	0.23	-3.69	-0.48 _i	0.88 _#	0.35	-0.15	-0.21	0.17	0.17	-0.11	0.06
Own	23.22	0.26	0.56	11.01	0.30	0.24	0.03	-0.31	0.09	0.69	0.50 _i	-0.10	0.49
R ²	0.40	0.40	0.40	0.47	0.68	0.51	0.52	0.27	0.10	0.20	0.58	0.26	0.59

* $p < 0.05$ _i

** $p < 0.01$ _i

_# $p < 0.10$ _i

238 confounding effects, we included sex, age (25 and below, over 25) and types of residence as additional variables. The results
239 show that several SCL-90-R scales are significantly associated with the family configurations that individuals have
240 constructed. On average, individuals with a Kinship Family Configuration show higher levels of symptomatology than
241 individuals in Professional, Nuclear, or Friendship Family Configurations.

242 Table 5 shows that the scores of the SCL-90-R scales are also sensitive to family configurations on the second interview
243 point. Again, individuals belonging to the Kinship Family Configuration have significantly higher scores of psychological
244 symptoms on several scales of the SCL-90-R than individuals from the three other clusters.

245 5. Discussion and conclusions

246 The diversification of family contexts in recent decades has had consequences for individuals with ID or mental health
247 issues (Mueller, Sapin, Gauthier, Orita, & Widmer, 2012). Although our study confirms previous findings that on average
248 family social capital of individuals with ID is low (Widmer, 2010), our results also show that individuals with ID develop a
249 variety of family contexts with distinct social capital, as it is the case in the general population. Kinship Family
250 Configurations provide less bonding social capital to individuals with ID than it is usually the case in generalist samples,
251 without granting them more bridging social capital. This finding is in line with previous research, which shows that Kinship
252 Family Configurations, despite their large size, develop only average levels of bridging social capital because a large number
253 of their members actually know each other and interact on a regular basis. The fact that no respondents in this sample report
254 an intimate partnership accounts for part of the low level of bridging social capital, as spouses and partners are bridges to
255 new family contexts. It is also notable, that Friendship Configurations do not create a higher level of bridging social capital in
256 this sample, contrary to what happens in generalist samples. This result arises from the fact that friends in this instance are
257 very much related with a shared residence, a situation that promotes regular contacts between them and the other family
258 members of the respondents. As for linking social capital, it is very strong in this sample compared with other samples, as
259 care professionals are seldom acknowledged as family members in the general population (Widmer, 2010).

260 The diversity of family configurations has consequences for the psychological adjustment of individuals with ID. Kinship
261 Family Configurations are associated with a higher level of symptomatology. Several considerations should be addressed
262 here. First, as stressed previously, these configurations have a low level of bonding, bridging, and linking social capital.
263 Therefore, they may not respond adequately to the demands of individuals with ID. Many individuals in such contexts may
264 feel left to themselves or with non-coherent family expectations and family support because of the lack of connections
265 among their significant family members. The impact of a lack of bonding social capital for individuals with ID has been
266 seldom addressed so far. The evidence of this contribution indicates that it is necessary to stimulate the development of
267 bonding, bridging, but also linking social capital made available by families to individuals with ID.

268 Indeed, care professionals play an important role in the personal network of individuals with ID (Forrester-Jones et al.,
269 2006; Stoneman & Crapps, 1990) and are perceived as family members by some of them. One should note that the inclusion
270 of care professionals as significant family members, while rare in the general population, was found in other therapeutic
271 settings as well (Widmer et al., 2008). Family configurations, therefore, also provide linking social capital (Szreter &
272 Woolcock, 2004) to individuals with ID. The family setting may make the connections between patients and care
273 professionals more intimate and less intimidating than does a formal definition of their professional roles. Connections with
274 care institutions may be more easily achieved and maintained by individuals with ID when care professionals are viewed as
275 family members. Interestingly, this study suggests that care professionals compensate to some extent for the absence of
276 parents in family configurations, even though most care professionals certainly do not consider themselves as family
277 members of their patients. A fascinating topic for further investigation would be the potential impact of the differences
278 between individuals with ID and care professionals in terms of their respective interpretations of the relationship.

279 Further questions arise about life trajectories and their effect on the family configurations of individuals with ID. Indeed,
280 previous studies on the general population show that family configurations stem from personal life trajectories (Widmer,
281 2010). For instance, the divorce and remarriage of parents, linked with the residential history of family members, have a
282 strong effect on the development of family ties (De Carlo, Aebly, & Widmer, 2012; Sapin, Widmer, & Radulescu, 2008; Vesela,
283 2011; Widmer, 2010). In this study, the amount of information about participants' life courses was rather scarce since, for
284 reasons of validity, respondents were not asked to provide chronological information about their lives. However, some
285 evidence did emerge in this case that the residential trajectories of individuals are key in understanding their family
286 configurations. The family configurations developed by individuals with ID indeed depend on their living arrangements.
287 Those who live with their parents and siblings more often develop a Nuclear Family Configuration. By contrast, individuals
288 who live in community residences have a larger share of care professionals and friends in their family configurations. The
289 residential situation of individuals with ID is part of a set of socioeconomic factors (Emerson & Hatton, 2008; Emerson et al.,
290 2010) which account for very distinct social experiences by persons with ID, with likely consequences for their psychological
291 adjustment.

292 In any case, the lack of research on family configurations from the viewpoint of individuals with ID rather than from the
293 perspective of their family members is striking. Instead of assuming from the start that only parental support matters for the
294 psychological adjustment of adolescents and young adults with ID, researchers should pay more attention to the diversity of
295 their family configurations. In this perspective, the usual distinction between social fields—such as work, friendship, and
296 family—may not be as clear-cut as is often believed to be. The results of this exploratory study suggest that care professionals

and friends are sometimes considered as family members and that, from the perspective of the individuals with ID, they may play significant family roles.

This study relied on a small purposive sample and as such had mostly an exploratory dimension. The facility that granted us contacts to its population includes a large spectrum of individuals with distinct socioeconomic backgrounds and citizenship status in their family of origin. There is also a diversity of comorbidity diagnosis in the facility, but we chose to interview only individuals without a comorbidity, in order to insure some homogeneity which compensates for the small sample size. Additional studies based on large and representative samples are needed in order to more precisely assess the diversity of family configurations of individuals with ID and their relation with psychological adjustment.

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