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Highlights

Family burden related to clinical and functional variables of people with intellectual disability with and without a mental disorder

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► Functional disability, especially in the areas of personal care and participation in society, explains the higher levels of family burden in caring for people with ID and ID–MD. ► The presence of behavioral problems and affective and psychotic disorder also cause higher levels of family burden. ► People with ID–MD generate higher levels of family burden in their caregivers than people with ID only. ► Effective treatments to reduce functional disability and symptoms in people with ID and ID–MD are needed in order to reduce family burden. ► Support interventions could help families to reduce their perception of family burden and to improve their quality of life.

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ABSTRACT

Few studies have been found that to assess the factors that explain higher levels of family burden in adults with intellectual disability (ID) and intellectual disability and mental disorders (ID–MD). The aims of this study were to assess family burden in people with ID and ID–MD and to determine which sociodemographic, clinical and functional disability variables account for family burden. The sample is composed of pairs of 203 participants with disability and their caregivers, of which 33.5% are caregivers of people with ID and 66.5% of ID–MD. Assessments were performed using scales of clinical and functional disability as the following instruments: Weschler Adult Intelligence Scale–III (WAIS–III), Inventory for Client and Agency Planning (ICAP), Psychiatric Assessment Schedule for Adults with Development Disability (PAS–ADD checklist), Disability Assessment Schedule of the World Health Organization (WHO–DAS–II) and family burden (Subjective and Objective Family Burden Inventory – SOFBI/ECFOS–II). People with ID–MD presented higher levels of functional disability than those with ID only. Higher levels of family burden were related to higher functional disability in all the areas ($p < 0.006–0.001$), lower intelligence quotient ($p < 0.001$), diagnosis of ID–MD ($p < 0.001$) and presence of organic, affective, psychotic and behavioral disorders ($p < 0.001$). Stepwise multiple regression showed that behavioral problems, affective and psychotic disorder, disability in participation in society, disability in personal care and presence of ID–MD explained more than 61% of the variance in family burden. An integrated approach using effective multidimensional interventions is essential for both people with ID and ID–MD and their caregivers in order to reduce family burden.

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1. Introduction

13 Conservative estimates suggest a worldwide prevalence of intellectual disability (ID) of 0.9–1.7% (Maulick,
14 Mascarenhas, Mathers, Dua, & Saxena, 2011) although higher rates are reported for low- and middle-income countries
15 (Durkin, 2002). The burden and costs associated with intellectual disability, which comprises a broad array of different

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health conditions, has been widely recognized to be high, yet there is a large **division** between the availability of services and the health needs of affected individuals (Salvador-Carulla & Saxena, 2009). The service gap is particularly great in those suffering ID and co-occurring mental disorders (ID-MD) (Cooper, Smiley, Morrison, Williamson, & Allan, 2007a). The point prevalence of associated psychiatric disorders in ID is about 40% (including **behavior problems**) (Bailey, 2007; Cooper et al., 2007a; Deb, Thomas, & Bright, 2001) and an annual incidence of 8% has been reported (Smiley et al., 2007). Although people with ID can suffer from the whole spectrum of psychiatric disorders, some are notably more common than in the general population. Among the most commonly associated diagnoses are non-affective psychosis (Salvador-Carulla, Rodríguez-Blázquez, Rodríguez, Pérez-Marín, & Velasquez, 2000; Cooper et al., 2007b) and bipolar disorder (Cooper, Smiley, Morrison, Williamson, & Allan, 2007c). ID-MD is also frequently linked to problem behaviors, which have prevalence around 20% in this population (Deb et al., 2001; Holden & Gitlesen, 2004; Lowe et al., 2007).

The concept of family burden was imported to the study of ID from the mental health field. Studies assessing burden in families with children with autistic, physical and intellectual disability have found that heavier costs and other burdens develop in the course of raising such children than in raising children without special difficulties (Xion et al., 2010). However, fewer studies have looked at the families of adults with ID, even though the burden on families providing informal care for adults increased with the rise of psychiatric community services (Mandelbrote & Folkard, 1961). Some researchers have pointed out that less attention has been paid to burden in the informal care of people with ID-MD (Maes, Broekman, Dosen, & Nauts, 2003; Wodehouse & McGill, 2009).

Family burden is a complex **construct, which** includes very different domains ranging from family routines to number of caring hours, social support networks and out-of-pocket expenses. Therefore, a holistic view should include the understanding of family burden in biopsychosocial framework (World Health Organization [WHO], 2001). One study of unpaid caregivers of people with learning disabilities referring to intellectual disabilities in the United Kingdom found that 75% of caregivers of an adult with ID had been caring for more than 20 years, 26% reported not being in paid employment due to their responsibilities, and 48% spent 100 or more hours a week caring for that person (Emerson et al., 2010). However, 90% of those caregivers felt they were or were usually involved as much as they wanted to be in decisions about the care and treatment of the person they cared for. **Care giving** in mental disorder may also generate worry, shame and **guilt**. **Researchers** have reported that families can suffer from the stigma associated with the disorders of the persons they care for (Schene, 1990; Szmukler et al., 1996; Tessler & Gamache, 1995).

Caregivers of people with ID and ID-MD may perceive their personal situation as stressful and consider that they lack effective strategies or sufficient resources to cope (Lazarus & Folkman, 1984; Maes et al., 2003). Personal, family, and context factors are the modulators of parental stress in the degree of adaptation to the family situation (Kim, Greenberg, Seltzer, & Krauss, 2003; Maes et al., 2003; Orsmond, Seltzer, Krauss, & Hong, 2003), with older caregivers experiencing less family **burden** (Chou, Lee, Lin, Kröger, & Chang, 2009). People with ID plus mental and behavioral disorders generate higher levels of demand, more caring hours and a need for assistance with personal care (Greenberg, Seltzer, & Greenley, 1993; Heller, Miller, Q3 and Factor 1997; Pinquart & Sörensen, 2006; Winefield & Harvey, 1993). Our group recently evaluated family burden in three groups of support service users (ID, ID-MD and schizophrenia), demonstrating the highest level of burden in ID-MD users (Martorell, Gutiérrez-Recacha, Irazábal, Marsà, & García, 2011).

Functional disability is usually defined as the difficulty or inability to independently perform basic activities of daily living or other tasks essential for independent living without assistance. People with ID presented higher levels of functional Q4 disability. (2008) Carr et al. (2008) show that people with ID had greater limitations in terms of autonomy; Määttä, Tervo-Määttä, Paanila, Kaski, and Iivanainen (2006) describe greater problems in verbal capacity and Bertoli et al. (2011) found that, in people with ID, problems with daily activities increase over time. Moreover, a number of problems arise in daily activities in people with MD, especially in those with severe mental problems (Viertiö et al., 2011; Kurzban, Davis, & Brekke, 2010). So, the functional disability in people with ID-MD is expected to be greater.

According to the literature revision only, Heller and Factor (1991) have related social functioning of adults with ID and ID-MD to family burden, showing that worse social functioning of adults with ID-MD is related to higher levels of family burden. Fewer studies have related family burden to clinical and functional disability in adults ID and ID-MD.

Following on from the previous studies, we expected that family burden would be greater in ID-MD than in ID as a result of the additional factors of mental disorder and associated behavioral disorders and higher functional disability in the service user. Since there has been little study in this area and data are somewhat hazy, our aim was to provide additional information on the subject. In one single study, we have included the most important aspects from the limited literature available (sociodemographic and clinical factors and functional disability) that influence family burden. Therefore, the aims of the present study were to assess family burden in people with ID and ID-MD and to determine which sociodemographic, clinical and functional disability variables explain higher levels of family burden.

2. Material and methods

2.1. Design and procedures

This observational cross-sectional study was carried out in two institutions providing community care in the two largest cities in Spain, Barcelona and Madrid; the participating facilities provide care for adults with mild or moderate ID with or

without MD. The ethical standards proposed for research in ID (Veenstra et al., 2010) were followed and the study was approved by the two centers' independent research ethics committees.

To recruit participants at each center, the head of the team responsible for coordinating the support service user's care sent a written explanation of the aims of the study to the family, requesting written informed consent from both the service user and the main caregiver. The participant and the caregiver were then referred to a trained psychologist, who gathered data for the study during two interviews, one with the participant and the other with the caregiver. Two trained psychologists, one in each center, carried out the interviews. At the time of data collection, the written informed consent of each participant (user and caregiver) was confirmed and aspects of confidentiality and data protection were explained.

2.2. Participants

We consecutively recruited, as described above, adults with mild or moderate ID with or without an associated mental disorder according to the International Classification of Diseases World Health Organization (ICD-10), [WHO, 2002], who lived in the community served by each center. Pairs of participants with ID and ID-MD and their main family caregivers were eligible to participate in this study.

The two participating centers were Parc Sanitari de Sant Joan de Déu (Barcelona) and the Carmen Pardo Valcarce Foundation (Madrid). The ID-MD group participants were included from occupational workshop and two specialist mental health units of Parc Sanitari Sant Joan de Déu. The ID group participants were included from the sheltered employment program and sheltered workshops of Carmen Pardo Valcarce Foundation. Inclusion criteria were living in the community, age between 18 and 65 years, and a diagnosis of ID or ID-MD.

A total of 217 participants with ID-MD ($n = 140$) and ID ($n = 77$) were enrolled, although only 203 family caregivers agreed to participate in the full test battery. Table 1 shows the description of participants with ID and ID-MD and family caregiver's characteristics (Table 1). No clinical differences were found between the 14 participants whose main family caregiver did not agree to complete all interviews, and who were therefore excluded from some analyses, and those who participated fully ($\chi^2 = 8.42$; $g.II = 5$; $p = 0.134$).

Table 1
Description of participants with ID and ID-MD and family caregiver's characteristics.

Variables	Groups		Statistics	
Participants data	ID	ID-MD		
	$N = 77$	$N = 140$		
	$n(\%)$	$n(\%)$	χ^2	p Value [*]
Gender				
Man	51(66.2%)	80(57.1%)		
Woman	26(33.8%)	60(42.9%)	1.716	0.190
Age	Average (SD)	Average (SD)	Student-t test	p Value [*]
	29.17(7.29)	29.54(6.88)	-0.36	0.713
Functional disability (WHO-DAS-II)				
Comprehension and communication	1.77(0.73)	1.56(0.91)	1.63	0.104
Environment mobility	1.11(0.38)	1.83(0.99)	-7.30	<0.001
Personal care	1.47(0.62)	1.98(0.94)	-4.63	<0.001
Relationships with others	1.88(0.88)	2.22(1.03)	-2.30	0.022
Daily life activities	1.73(0.81)	2.20(1.04)	-3.48	0.001
Participation in society	1.45(0.51)	1.97(0.81)	-5.58	<0.001
Intellectual quotient	57.27(6.84)	54(6.65)	2.25	0.010
Caregivers data				
	$n(\%)$	$n(\%)$	χ^2	p Value [*]
Gender of caregivers				
Woman	59(86.8%)	111(82.2%)		
Man	9(13.2%)	24(17.8%)	0.685	0.408
Relationship with the adult (users)				
Mother	55(80.9%)	107(79.3%)		
Father	9(13.2%)	21(15.6%)		
Siblings	4(5.9%)	5(3.7%)		
Grandparents	0(0%)	2(1.5%)	1.67	0.643
Age of caregivers	Average (SD)	Average (SD)	Student-t test	p Value [*]
	58.51 (8.73)	59.30 (9.67)	-0.63	0.347

* $p < 0.05$ was considered significant.

98 2.3. Instruments

99 The following five tests or recording instruments were used to collect data reflecting family burden and
100 sociodemographic, clinical and functional disability variables.

101 The Spanish version of the **Weschler** Adult Intelligence Scale, third edition (WAIS-III) (**Weschler**, 1999), was used to
102 measure the service users' intelligence quotient (IQ). The IQ was assessed in the interview conducted with the participants
103 (ID and ID-MD).

104 The remaining instruments, listed below, provided information about both service users and caregivers. The following
105 instruments were assessed in an interview with the family caregiver.

106 The Inventory for Client and Agency Planning (ICAP) (**Bruininks, Hill, Weatherman, & Woodcock**, 1986) was used to collect
107 records related to the diagnosis, personal data and functional limitations of each user. On this management instrument,
108 adaptive behavior is measured on four scales (motor skills, social skills, personal life skills and community-living skills). The
109 general independence scale provides information on services and support available to the individual. The Spanish version of
110 the ICAP has shown high internal consistency (Cronbach alpha, 0.85) and good inter-rater reliability (Cohen kappa statistic,
111 >0.75) (**Montero**, 1996).

112 The semi-structured **subjective and objective family burden interview** (ECFOS-II) was first developed for the analysis of
113 family burden in schizophrenia (**Vilaplana et al.**, 2007) and later adapted to ID (**Martorell, Pereda, Salvador-Carulla, Ochoa, &**
114 **Ayuso-Mateos**, 2007). The instrument gives scores for caregivers' responses in nine modules referring to assistance with
115 daily life activities, problematic behavior supervision, financial burden, impact on career's life, worries about patient's life,
116 available help, career's health consequences and a global evaluation of burden. These modules can be used and interpreted
117 independently as there is a score for each. The total ECFOS-II score was calculated in two phases. The sum of all the variables
118 included in each module was calculated first, transforming that value into a score between 0 and 12. The second phase
119 involved calculating the mean of the first eight modules to obtain a total score between 0 and 12. Higher scores indicate
120 greater family burden (**Marsà**, 2010).

121 ECFOS-II has shown high internal consistency (Cronbach alpha, 0.88) and test-retest reliability (range, 0.61-1 for the
122 different modules) in family caregivers of persons with ID (**Vilaplana et al.**, 2007; **Martorell et al.**, 2007).

123 The checklist of the Psychiatric Assessment Schedule for Adults with Development Disability (PAS-ADD) (**Moss et al.**,
124 1998) was used in its the previously validated Spanish version (**González-Gordon, Salvador-Carulla, Romero, González-Sáiz,**
125 **& Romero**, 2002). This semi-structured interview for psychiatric diagnosis in ID, whose feasibility has been analyzed in 14
126 European countries including Spain (**Perry et al.**, 2010) consists of two sections. The first evaluates the presence or otherwise
127 of stressful life events and the second comprises a total of 25 items with four response options. Three global scores are
128 obtained related to affective, psychotic and organic-type problems. The affective score ranges from 0 to 28; the psychotic
129 score ranges from 0 to 6 and the organic-type problems score ranges from 0 to 8. Scores over a determined threshold indicate
130 a need for a more detailed psychologic evaluation. Inter-rater reliability, according to **Perry et al.**, has ranged between 0.65
131 and 0.7. The agreement for case vs. non-case assessment was over 90%.

132 The Disability Assessment Schedule of the World Health Organization (**WHO-DAS-II**, 2000) assesses 36 items with a range
133 of response of 0-5 (**Garín et al.**, 2010). The six subscales include comprehension and communication, personal care,
134 relationships with others, daily life activities, participation in society and functional difficulties associated with mobility
135 within the environment. The reliability of the different subscales of the Spanish version ranged from 0.40 to 0.74 (interclass
136 correlation coefficients) (**Vázquez-Barquero et al.**, 2005).

137 2.4. Data analysis

138 Data were entered into SPSS v.17 for Windows (SPSS Inc., Chicago, IL) for statistical analysis.

139 The comparison of the two profiles of users (ID vs. ID-MD) and their caregivers were performed by **Student t-test** for
140 quantitative variables and chi-square test for qualitative variables. The level of significance was set at $p < 0.05$. The Pearson
141 correlation and **Student t-test** were used to compare the clinical, functional disability and sociodemographic variables by
142 family burden and explore associations. Finally, a stepwise regression analysis was done to determine which
143 sociodemographic, functional disability and clinical variables accounted for higher indexes of family burden. The stepwise
144 method included in the one-to-one model the variables that explain part of the variance in overall family burden.

145 The variables included in the model were those we found to be significant in the previous analysis.

146 3. Results

147 No differences were found in the control variables (gender and ages of either users or caregivers between the two
148 diagnostic groups) (**Table 1**) except for IQ being IQ higher in the ID group ($t = 2.25$; $p = 0.01$). The different areas of functional
149 disability evaluated by the WHO-DAS-II were statistically higher in the ID-MD group in the following areas: mobility in the
150 environment ($t = -7.30$; $p < 0.001$); personal care ($t = -4.63$; $p < 0.001$); relationships with others ($t = -2.30$; $p = 0.022$);
151 daily life activities ($t = -3.48$; $p < 0.001$); and participation in society ($t = -5.59$; $p < 0.001$). With respect to clinical
152 characteristics, statistically significant differences were found between ID and ID-MD participants in the three types of
153 symptom of clinical severity: organic condition ($t = -6.542$; $p < 0.001$), affective disorders ($t = 10.769$; $p < 0.001$) and

Table 2
Relation between sociodemographic, clinical and functional disability variables to family burden.

Total family burden		
	Average (SD)	p Value [*]
Gender		
Men	3.28 (2.27)	0.237
Women	3.62 (2.03)	
Diagnosis		
ID–MD	4.17 (2.15)	<0.001
ID	2.02 (1.41)	
	Pearson's coefficient	p Value
Age of the participant	–0.006	0.929
Age of the mother	–0.046	0.474
Age of the father	–0.041	0.529
Organic diagnosis	0.501	<0.001
Affective diagnosis	0.609	<0.001
Psychotic diagnosis	0.491	<0.001
Behavioral disorders	0.591	<0.001
Comprehension and communication	0.330	<0.001
WHO-DAS-II		
Functional difficulties associated with mobility within the environment WHO-DAS-II	0.174	0.006
Personal care WHO-DAS-II	0.519	<0.001
Relationships with others WHO-DAS-II	0.312	<0.001
Daily life activities WHO-DAS-II	0.460	<0.001
Participation in society WHO-DAS-II	0.587	<0.001
Total punctuation WHO-DAS-II	0.588	<0.001
Intellectual quotient (IQ)	–0.242	<0.001

^{*} $p < 0.05$ was considered significant.

Table 3
Clinical and functional disability variables associated with family burden.

Variables included in the model	B	p Value [*]
Affective disorder	0.055	0.028
Personal care WHO-DAS-II	0.160	<0.001
Participation in society WHO-DAS-II	0.092	<0.001
Psychotic disorder	0.341	<0.001
Behavioral disorders	0.037	<0.001
Presence ID–MD	0.494	0.025
R^2 adjusted = 0.616		

Variables excluded from the model: IQ, organic symptoms, communication and comprehension WHO-DAS-II, relationships with others WHO-DAS-II, daily life activities WHO-DAS-II and functional difficulties associated with mobility within the environment WHO-DAS-II.

^{*} $p < 0.05$ was considered significant.

154 psychotic disorders ($t = -7.047$; $p < 0.001$). Those with ID–MD obtained the highest scores for PAS–ADD checklist items. The
155 severity of behavioral problems, measured by the ICAP, was significantly greater ($t = -7.74$; $p < 0.001$) in people with ID–MD
156 ($t = -3.70$) than in those people with only ID ($t = -3.31$).

157 In the comparison between caregivers, statistically significant differences were found in the mothers' working situation
158 ($\chi^2 = 13.209$; $p = 0.004$), with the ID–MD having a higher percentage of retired mothers. A higher number of caregivers of
159 individuals with ID–MD also dedicated a large number of hours a week to provide care (>28 h/wk for 76.7%) in comparison
160 with the caregivers of participants with ID ($\chi^2 = 6.139$) ($p = 0.022$).

161 Table 2 shows the correlation coefficients for sociodemographic, clinical and functional disability variables in relation to
162 higher family burden. People with ID–MD showed higher levels of family burden than people with ID ($p < 0.001$). A diagnosis
163 of affective, organic and psychotic ($p < 0.001$) and presence of behavioral problems ($p < 0.001$) were related to higher levels
164 of family burden. Moreover, higher scores in functional disability (WHO-DAS-II) showed higher family burden. Lower IQ was
165 related with higher levels of family burden ($p < 0.001$).

166 Table 3 shows the clinical and functional disability variables associated with family burden. The model developed
167 accounts for 61.6% of the variance in perception of caregiver family burden. The variable that explained the greatest amount
168 of variance (37.6%) in the model was presence of affective disorder. When personal care (WHO-DAS-II) was included, the
169 model explained an additional 11.5% of the variance in total of family burden, so that the two-variable model explained a
170 total of 49.1% of the variance. The next variables included were as follows: participation in society (WHO-DAS-II) (which
171 explained an additional 6.8% of the variance), psychotic disorders (explaining an additional 2.6% of the variance), behavioral
172 disorders (an additional 2.2%), and presence of mental disorders associated with the ID (an additional 0.9%). With these
173 additions, the six-variable model explained a total of 61.6% of the variance.

174 **4. Discussion**

175 This study explored the profile of family caregivers and the related factors of family burden in persons with ID and ID-MD
176 using specialized services for persons with ID in the two largest cities in Spain. To our knowledge this is the first study to
177 assess the clinical and functional disability variables together in the same study in relation to family burden in ID and ID-MD
178 population.

179 The main results of our study show that clinical and functional disability variables and having MD associated (being in the
180 ID-MD group) explain higher levels of family burden in comparison with only having ID. Specifically the clinical and
181 functional disability variables that explain higher degrees of family burden in ID-MD were: presence of behavioral, affective
182 and psychotic disorders and greater disabilities in the areas of participation in society and personal care.

183 The profile of people with ID and ID-MD is similar with respect to sociodemographic characteristics, although some
184 differences emerged in their clinical and social functioning. People with ID-MD present more functional disability in several
185 areas of the WHO-DAS-II than people with ID. Few studies have assessed the functional disability comparing ID and ID-MD.
186 Consistent with our results, Bouras et al. (2004) found that people with ID and schizophrenia have lower functioning than
187 those with ID alone.

188 Participants with ID-MD presented a high rate of affective, psychotic and behavioral disorders, as found in other studies
189 on prevalence of mental disorders (Martínez-Leal et al., 2011; Maes et al., 2003; Hemmings, Tsakanikos, Underwood, Holt, &
190 Bouras, 2008). We should stress that several differences emerged in the characteristics of these studies, although all the
191 results are concordant. This finding was therefore expected, confirming the agreement between the clinical criterion (ICD-
192 10) and the evaluation of symptoms using the PAS-ADD checklist.

193 In our study a low level of total family burden was found (lower than 5 considering the range is between 0 and 12),
194 possibly due to the characteristics of the sample of users living in the community and having less severe functional
195 disability. Another possible explanation might be that the sample consists of Hispanic families who, according to
196 Jenkins (1988) and Seltzer et al. (1995), show greater acceptance of disability and/or mental disorder affecting those in
197 their care and also to informal care patterns in severe mental illness in Spain (Salvador-Carulla, Costa-Font, Cabetes,
198 McDaid, Alonzo, & 2010). Moreover, Chou, Fu, Lin, and Lee (2011) found that older caregivers present lower levels
199 of family burden, consistent with our results because the average age of the caregivers in our sample was around
200 60 years old.

201 We emphasize that the caregivers of people with ID-MD in this study perceived a greater family burden than the
202 caregivers of those with ID only. Maes et al. (2003) and Emerson et al. (2010), found similar results in caregivers of child and
203 adult with an ID-MD. The presence of behavioral problems, psychotic and affective symptoms increases the risk of having
204 greater family burden. Other authors have found that either behavioral problems or psychotic symptoms contribute to
205 explain higher rates of family burden both in people with ID and ID-MD (Maes et al., 2003; Matthews, Weston, Baxter, Felce,
206 & Kerr, 2008; Kim et al., 2003). McIntyre, Blacher, and Baker (2002) also found greater family burden in people with
207 behavioral problems.

208 Related to functional disability, the disability in participation in society and personal care are the main areas that
209 contribute to higher family burden. Other authors indicate that disability in social contexts helps to explain family burden
210 (Maes et al., 2003; Miltiades & Pruchno, 2001). When there is impairment in basic functions such as personal care,
211 dependence is greater, with a negative effect on family burden. When persons do not engage in social interaction, or have
212 greater communication difficulties, they may be more isolated, spending longer hours in the home, also generating greater
213 family burden.

214 One of the possible limitations of the study is that some caregiver variables, which can mediate burden have not
215 been included. Carers' coping strategies or attributional style, for example, have not been studied. Another limitation is
216 that the nature of a cross-sectional study allows us to establish relationships between variables but not to identify
217 longitudinal predictors of increased family burden. The final limitation that we would like to mention is that all the
218 participants were enrolled at one of two centers and, as such, are possibly not representative of the whole population
219 with ID or ID-MD.

220 Considering both clinical and functional disability aspects allows the development of community-based interventions
221 with the aim of creating an appropriate network of social support, which can alleviate perceived global burden in caregivers
222 of people with ID and ID-MD (Bax, 2000). The recently approved Spanish Dependency Law (BOE, 2006) considers caregivers'
223 needs and tries to compensate for the time spent in the care of offspring or other dependents. Valuable initiatives would be
224 the setting up of caregiver relief services (respite care), such as psychoeducation programs, mutual-help support groups,
225 professional emotional and psychosocial support, as others have suggested (Cooper et al., 2007a; Hemmings, 2008).
226 Interventions that address the reduction of the functional disability and symptoms of people with ID and ID-MD could also
227 help to decrease the perceived family burden of the caregivers. Effective interventions based on the multidimensional
228 approach proposed by the WHO (2001) and by the American Association on Intellectual and Developmental Disabilities
229 (Luckasson et al., 2002), which also address the abilities and difficulties of the people with ID, should be undertaken. It is first
230 necessary to identify the support required by people with ID in their effort to acquire coping skills that facilitate social
231 integration (Verdugo, Cordoba, Restrepo, Cardona, & Peña, 2009). Aspects such as social adjustment and communication
232 skills are important for the person's ability to function in a social context, with consequent improvement in quality of life
233 and reduction in caregiver burden.

234 **Uncited references**235 Q5  **Hatton and Sevin (1994) and Salvador-Carulla and Bertelli (2008).**236 **Acknowledgements**

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