

Families with Intellectual Disability Members: The Kind of Perceived Parents' Needs

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ABSTRACT

Objective: The family needs of parents with children who have been diagnosed with Intellectual Disability (ID), have received attention in outcome research. The purpose of this study was to investigate the family needs of parents who have children with intellectual disability and examine their relationship with their demographic characteristics. **Method:** The research involved 134 parents of children have been diagnosed with ID and responded to the questionnaire through a structured interview. The relationship between variables of interest and participants' demographic characteristics was also analyzed. **Results:** The analysis of our collected data showed that parents expressed needs for more information, social support, and counseling services. In terms of demographic variables it was found that parents with younger children reported a small number of needs for social support and counseling services compared to parents of older children. In addition older parents reported more needs compared to younger parents.

Keywords: family, intellectual disability, parents, needs

INTRODUCTION

Intellectual disability (ID) is the most studios and also the most heterogeneous group both in terms of etiology and social adjustment. The concept of ID is controversial, as the concept of intelligence has not been defined in a generally accepted way, given that intellectual capacity is related to the relationship and position of the individual in the social stratification. Studying the path of relevant terminology, one encounters terms such as mental disability, mental retardation (delay), and severe learning difficulties¹. The change in the terms used from time to time shows the connection of the community with the phenomenon, so any change in its conditions is reflected in the evolution of terminology². In the United States of America (USA) the former term mental retardation has been replaced by the term "intellectual disability" reflecting the shift to an ecological approach that focuses on the environment and its interaction with the individual, recognizing the importance of individualized educational programs, "while in United Kingdom this change has been relatively silent"³. ID is considered as something more

than a biomedical condition or a psycho-educational deficit. It should be recognized as a social construction and defined as a lack of social adjustment and absence of expected social behavior⁴. It is characterized by significant deficits in both intellectual and adaptive functions of the individual and is expressed on a mental, social, and practical level starting during the developmental period. These deficits reflect a) a significant weakness or limitation in the individual's functional capacity and in the achievement of social roles and tasks b) it concerns a substantial disability of the individual c) it can be influenced by many factors and d) these deficits can be reduced through effective interventions and support⁵. The first definition, as formulated by the American Society in 1959, focused on biological factors without taking into consideration the potential existence of socio-cultural factors. It was essentially a personalized and medical effort to understand the disorder and eliminating any form of social dimension.

Nowadays, it is obligatory to redefine the relationship between "normality" and "irregularity". A new orientation and a new approach is necessary, giving more focus to the capacities of the same person, to the environment in which he lives and works as well as to his functional level. It is no coincidence that in recent years the research interest has focused more on the failure of modern society to deconstruct the social construct "mental retardation", to provide adequate education and adequate support to these individuals, instead of focusing on the weaknesses of individuals themselves. A child's disability is a triadic experience, involving three-way interactions among the child who experiences the disability, the family that is affected by it, and the external environment where the disability is developing.

ID cannot be considered as a characteristic of the individual, nor as a disease, but more as a social construction, in the declarative superiority expressed by the majority group of the "normal". The development of the child who have been diagnosed with ID can be conceived within a grid of social terms and conditions. This disability cannot be perceived as a purely individual phenomenon, but placed in a social context and not as a permanent disorder. According to Oliver and Barnes⁶ ID should be approached more as a product of social organization as opposed to a personal restriction of the individual. Developing promotion programs that place the family at the center of what is happening, requires a redesign of the methodology. It should be identified which family dimensions could be exploited, in order to offer more substantial support to the child. Family needs, family climate, the ecological view of the family duties and responsibilities as well as the impact of methodical support systems are the most current research dimensions of the family associated with mental retardation⁷.

Research interest in families of children with disabilities began in the late 1950s. Before the mid-1970s, families with disabled children were treated as a clinical entity with pathology. Pathological perception has a long history. It refers to ideas coming from 16th century Europe or even earlier on disability and mental retardation as due to biological reasons. In the 18th century, the reproductive insufficiency and "defectiveness" of the organic reproductive material was related to the moral degeneration, while in the 19th century these cases were connected with the hereditary predisposition. Subsequent studies show that this does not exist, and the stress that the whole family experiences come not only from having a child with difficulties, but it can be the result of various factors⁸. The most stormy and chronic emotions experienced by parents are usually mourning, sadness, frustration, despair that are mainly due to the frustration of expectations for their child. In addition, the lack of help from organized services, social indifference, stigma, and marginalization play an important factor too.

The "obsession" to approach disability as another social problem among many, and not as a version of diversity, led to the disclaimer of social responsibility towards the person with a disability and restored individual responsibility for its management.

When a family has a member with ID, that can affect family's life and the way different family subsystems communicate with each other. Disability in children gives rise to various needs in parents, which may vary according to the nature of disability and parental characteristics⁹. Most parents have various support needs that are frequently unmet¹⁰. Anger, rage, resentment, and discomfort are emotions that can be directed against society and "experts". They can turn from one partner to another and to the children of the family, even to God. Parents expressed their personal concerns about their child's ability to function in a less restrictive environment or in less sheltered settings, and were concerned about their child's future.

Needs have been defined as the basic requirements expressed by an individual in order to survive. Survival in society needs expressed by an individual or families are social support, information, financial support, childcare needs, professional support and community services. Needs expressed by families of children with ID vary from person to person and from family to family. Cross-cultural researches will assist in understanding the process of meeting these needs, which ultimately help in designing appropriate interventions.

Parents themselves do not know how to behave and respond to their children's needs and are tormented by "doubts about their reproductive ability". Wikler and colleagues¹¹ reported that there are three types of reactions to the grief experienced by parents of individuals with disabilities:

1. Decreasing sadness over time and complete overcoming of mourning
2. Chronic sadness and feelings of frustration
3. Emotional "ups and downs" with increased sadness at times, when serious developments in the child's life are signaled.

Main purpose of evaluating family needs is to provide a contribution to children with ID and to settle the type, content, and quality of the service which will be provided to the child and to the family. For that reason problems that families have after they found out that they have a child with ID should be determined, in addition to family needs their strong ways and their supports should be settled. Having a child with intellectual disability, requires solving difficulties such as child care, doing the house work, coping with negative emotions that family members feel for each other, undertaking financial drain of family, fulfilling roles and duties of family members, planning the time for leisure times, relaxation, amusement events and tasks they have to do, carrying on with family intercommunication such as protecting each other, creating mutual peace atmosphere, supporting each other, being tolerant toward each other, taking realistic decisions for the child. This situation requires the need of coping with the difficulties of fulfilling family functions¹².

Winton¹³ indicated that in order to determine families' needs five informational areas should be evaluated which are the following: properties of child, information, help and support, nature of the interactive relation between child and parents, point of view of the family for upbringing the child and living with a child with disability, and families' lifecycle and conditions. Generally analyzed, within the needs of parents of child with intellectual disabilities, need of

knowledge/education, need of support, need of performing family function properly are emphasized frequently. In need of knowledge/education category, families' need of knowledge/education takes part in these kind of subjects; nature and properties of disability, child's and family's legal rights, offer education to the child, preparing an efficient environment for child's education at home, coping with child's behavioral problems and communication with the child¹⁴. To be able to limit the expectations from child with intellectual disabilities as members of his family, to determine the convenient purpose and service fulfill the families' needs of information about child's disability, property and legal rights is essential. The researches^{15,16} identified that the informative counseling for the parents' needs of knowledge/education reduces the concern and stress and support their adjustment process.

Family with disabilities is a system with distinct life cycles, which are accompanied by stages of development, change, and decay. The family whose member has been diagnosed with ID cannot function as an autonomous system, since other frameworks coexist which play an important role. The friendly and direct social environment essentially influences the system in terms of its internal and external composition and operation.

This environment can help, but at the same time determines whether the family will experience isolation, stigma, and rejection¹⁷. The existence of a child with disabilities follows a number of specific stages within the family. Confirmation of a serious and chronic problem often creates a crisis which affect the whole family system.

Common reactions of negative emotions that could be acknowledged to these families at all stages of their life cycle includes the following¹⁸:

1. Protection of the defenseless, e.g., strong feelings of protection for the infant and child
2. Aversion to abnormal, e.g., feeling of anxiety, sadness and disgust towards the disabled
3. Reproduction problems, e.g., feeling that something is wrong with them as parents because they have "produced" a "defective" child
4. Sufficiency of upbringing, e.g., the feeling that as parents they are inadequate
5. Anger, e.g., feeling angry from "life" and "fate" itself
6. Sadness, e.g. grief for the problems of the child that they bring to life
7. Guilt, e.g., feelings of guilt when something happens to the child

As of the time the needs of families with children with disabilities were mainly determined by the point of view of experts. The new trend in favor of involving parents in needs assessment, foreshadowed a major shift to a demand-based theory and was based on the needs of the users themselves⁸. According to the Negotiation Model, which also characterizes our theoretical approach, the needs assessment process should be conducted through the negotiation of a cooperative with the family. Family needs assessment should aim to identify family's recent needs over a specific period of time. It should be individualized and family-centered taking into account the needs of each member as well as the entire family system.

Research data⁸ have come to an end that families with children with disabilities have a variety of needs, which are classified into categories such as: Information, counseling, support, practical assistance as well as participation in diagnostic and evaluation procedures.

General Characteristics of the research

The present study aims to investigate the type of family needs that have an individual with ID and in particular to identify the most frequently reported needs of both parents and to study the relationship between parental needs and demographic variables. In particular, the research questions concern the effect of demographic characteristics of parents (i.e., gender, age, educational level, profession) on the number of needs of individuals per category and the number of needs per category in terms of demographic characteristics of people with ID. In terms of its general reflection and philosophy, our research is part of the scientific field described by Clinical Psychology. The assessment of family needs was based on the model of Negotiation, i.e., the creation of a "partnership" with the family in order to facilitate both the identification of their needs and their active participation in the evaluation process.

The research process applied in our research focused on the exploratory-descriptive strategy investigating these needs in a series of variables as they are described and presented in the international literature.

METHOD

Sample selection

As part of the research, the perceptions of family needs with children who had previously been diagnosed with mild intellectual disability by the Child Psychiatric Department services in Greece, were investigated

Procedure of data collections and data analysis

Each parent was contacted to ensure his participation in this research study. After signing a written consent form in order to indicate voluntary participation in the study, parents were asked to complete the scales. Subsequently, the parents who agreed to participate in the survey were analytically informed during lunch or afternoon meetings.

Data were collected by using statements-report from the Extended Family Needs Survey by Bailey Simeonson¹⁹ as reported by Granlund and Roll-Pettersson²⁰, and the Family Needs Survey and Ability Index as reported by Roll-Pettersson²¹.

In total 150 questionnaires were forwarded but 16 of them were not included in the analysis due to insufficient completion (i.e., **response rate 92.6%**). Initially, there was a telecommunication with the parents where their consent to the research was initially requested and then they were thoroughly informed regarding the research purposes via Skype. The questionnaires were sent to the parents via email after consultation between the period of December 12th to January 23rd of 2022.

Research design

This study utilized a descriptive and correlation research design. The objective was to examine the family needs of children with ID. In this study, research tools and data analysis came out from research instruments modified in Greek population.

Research instruments and data analysis

Data presented in this study came out from research instruments adapted in Greek population. The instruments which were applied are defined below:

The Extended Family Needs Survey by Bailey Simeonson (1990) as reported by Granlund and Roll-Pettersson (2001), and the Family Needs Survey and Ability Index as reported by Roll-Pettersson (2003).

Statistical analyses

The statistical package that was used during our current research study was the SPSS 25.0. Analysis of the quality of life was carried out on the subjective composite indices for each life domain. Normality was tested using the Kolmogorov-Smirnov test.

The percentage frequencies of the positive responses in each report were calculated, separately for fathers and mothers, so that the possibility of comparison would be possible.

Below has been reported the presentation of our findings separately for each category of needs.

RESULTS

Profile of sample: demographic characteristics

In our research study participated 134 parents of individuals with ID. Of the total sample, 58 were men (43.3%), and 76 women (56.7%) - aged 28 to 47 years (average 34.3 years, sd 4.26). A total of 61 parent couples participated, 5 married women and 7 divorced. The largest percentage of parents (76.2%) had two children, 14.5% had three and the rest had only one child.

Regarding their professional status, the majority 128 (95.5%) were employed and 6 (4.5%) were looking for a new job, as they had recently been fired from their previous position. Regarding children, 84 were boys (62.7%) and 50 girls (37.3%). The age ranged from 9 to 15 years (average 12.6).

The diagnosis for the 102 children (76.1%) was found out in the first 6 years of their lives by public hospitals and medical centers, while in the rest of the cases by private health professionals.

Table 1. Socio-demographic Characteristics of the Sample

	Fathers N=58	Mothers N=76
Age		
28-38 N=88(65.7%)	36(62%)	52 (68.4%)
39-47 N=46 (34.3%)	22(38%)	24(31.6%)
Educational level		
University education N=92(85.2%)	45(62.5%)	58(76.3%)
Secondary education N=42(14.8)	13(57.9%)	18(23.7%)
Occupational Status		
Employees N=128(95.5%)	56(96.5%)	72(94.7%)
No employees N=6(4.5%)	2(3.5%)	4(5.3%)

Below is the presentation of the findings separately for each category of needs.

Need for more information. Table 1 shows the frequencies and percentages of positive parental responses.

An overview of the table below shows that there is mostly a convergence of parents' views regarding the prioritization of their needs. In particular, both fathers and mothers were asking for more information regarding sex education and the handling of issues related to adolescence in a universal percentage (100%). In addition, 97.3% of mothers and 89.6% of fathers expressed their need for more information on how their child will grow and develop. Then there were the needs related to the psychosocial services of the future (i.e., mothers 92.1% & fathers 86.2) and the same percentage (92.1%), only for mothers the information about the handling of the child's behavior. The need for information on how to teach new skills (i.e., mothers 89.4% & fathers 65.5%), was recorded by both parents.

Finally, the need expressed with the lowest overall frequency was the information on how parents will communicate and play - interact with their child (47.7%), followed by the need for more information on their child's difficulties at a rate of 58.2%.

Table2. Parents needs for information. Frequency and percentages in rapports

<i>Do you need more information about...</i>	<i>Fathers (N=58) f (%)</i>	<i>Mothers (N = 76) f (%)</i>	<i>Total (N = 134) f (%)</i>
1. your child's difficulties	34 (44.7)	44(57.8)	78(58.2)
2. how to handle your child's behavior	40 (68.9)	70(92.1)	110(82.1)
3. how to teach your child new skills	38(65.5)	68(89.4)	106(79.1)
4. how to play and communicate with your child	22(37.9)	42(55.2)	64(47.7)
5. services that are available for your child	36(62.1)	46(60.5)	82(61.2)
6. services that may be available in the future for your child	50(86.2)	70(92.1)	120(89.5)
7. how your child will grow and evolve	52(89.6)	74(97.3)	152(94)
8. sexual education and how to deal with the difficulties of adolescence	58(100)	76(100)	134(100)

Table 3. Family needs for social support. Frequency and percentages in rapports

<i>Do you need ...</i>	<i>Fathers (N = 58) f (%)</i>	<i>Mothers (N = 76) f (%)</i>	<i>Total (N = 134) f (%)</i>
9. more time for yourself	32(55.1)	44(57.8)	76(56.7)
10. help to support the rights of your child and family (e.g., allowances, health insurance etc.)	30(51.7)	52(68.4)	82(61.2)
11. a family member who can express your concerns	24(41.3)	17(44.7)	41(43.2)
12. friends to talk to	36(62)	58(76.3)	94(70.1)
13. to socialize with parents who have children with similar difficulties	32(55.1)	54(71)	86(64.2)
14. to discuss more often with teachers for your child's academic skills	48(82.7)	72(94.7)	120(89.5)
15. to be informed through printed material, experiences and through other parents	42(72.4)	56(73.6)	98(73.1)
16. to participate in the configuration of the therapeutic program of your child	44 (75.8)	64(84.2)	108(80.5)
17. experts talk to you in a more understandable way	56(96.5)	72(94.7)	128 (95.5)
18. your child to have his own friends	58(100)	64(100)	122(100)
19. the experts who supervise your child to show you more understanding	50(86.2)	62(81.5)	112(83.5)
20. to find time for your other children	28(48.2)	38(50)	66 (49.2)
21. to find time for your friends	34(58.6)	50(65.7)	84(62.7)

Needs for social support

Table 3 also identifies parents' needs and more specifically their need their child to make friends and build social skills which was at a rate of 100%. This was followed by the need to communicate with professionals who supervise the child in such a way that it is understood by them (i.e., 96.5% of fathers & 94.7% of mothers).

The same percentage of mothers (94.7%) - and (82.7%) of fathers wanted to talk to teachers about their child's progress in the school unit, while 80.5% of the total wanted to participate in shaping their child's treatment plan. Finally less than a half of the parents (49.2%) - felt the need to find extra time for the rest of their children, while 43.2% of them needed a member of their family to express their various concerns and concerns.

Table 4. Family needs explaining the difficulties of their child. Frequency and percentages in rapports

<i>Do you need help explaining the difficulties of your child to...</i>	<i>Fathers (N=58) f (%)</i>	<i>Mothers (N = 76) f (%)</i>	<i>Total (N = 134) f (%)</i>
22. his siblings	22(37.9)	42(55.2)	64(47.8)
23. your parents	18(31)	20(26.3)	38(28.3)
24. your parents in-law	16(27.5)	32(42.1)	48(35.8)
25. your wife/ husband	8(13.8)	6(7.9)	14(10.5)
26. your friends	28(48.2)	30(39.5)	58(43.3)
27. your neighbors	14(18.4)	10 (13.1)	24(17.9)
28. strangers	10(17.2)	12(15.8)	22(14.9)
29. other children	30(51.7)	32(42.1)	62(46.2)
30. the rest of the family	10(17.2)	14(18.4)	24(17.9)

Needs for explanation of the difficulties of their child

Concerning the needs of the parents regarding their clarification of difficulties presented by their child, differences in the hierarchy of needs between fathers and mothers were recorded (Table 4):

More specifically, fathers prioritized the need to explain their child's difficulties to other children -51.7% -, then to friends-48.2%, to siblings 37.9% and to their parents 31%. On the contrary, mothers prioritized the explanation of difficulties to siblings -55.2%, to other children 42.1%, to friends 39.5%, followed by their parents at 26.3%.

Identity of views was recorded in terms of explaining the difficulties to the spouse, where the lowest value appeared in both genders.

Table 5. Family needs for ancillary services. Frequency and percentages in rapports

<i>Are you having a hard time...</i>	<i>Fathers (N=58) f (%)</i>	<i>Mothers (N= 76) f (%)</i>	<i>Total (N = 134) f (%)</i>
31. finding a specialist doctor	30(51.7)	52(68.4)	82(61.2)
32. finding a baby-sitter	22(38)	14(18.4)	36(26.9)
33. finding the right school for your child	38(65.5)	62(81.5)	100(74.6)
34. finding the appropriate space to care for your child after school	14(24.1)	18(23.6)	32(23.9)
35. finding an entertainment area for your child's free time	32(55.1)	48(63.1)	80(59.7)

Needs for ancillary services

Table 5 shows that both fathers and mothers considered it more difficult to find a suitable school for their child (81.5% for mothers and 65.5% for fathers), followed by finding a specialist doctor such as orthodontics (68.4% for mothers and 51.7% for fathers) and the entertainment area (63.1% for mothers and 55.1% for fathers). Finding a babysitter did not seem to be recorded in particular percentages in both parents.

Table 6. Frequency and percentages in rapports. Family needs for financial support

<i>You spend a lot of money...</i>	<i>Fathers (N =58) f (%)</i>	<i>Mothers (N = 76) f (%)</i>	<i>Total (N = 134) f (%)</i>
36. on your child's basic needs	24(41.3)	34(44.7)	58(43.3)
37. on special equipment	8(13.7)	14(18.4)	22(16.4)
38. on your child's treatments	42(72.4)	72(94.7)	114(85.1)
39. on baby- sitting	4(6.9)	2(2.6)	6(4.5)
40. on games	12(20.6)	10(13.1)	22(16.4)
41. on entertainment material (books, DVD etc.)	8(13.7)	6(7.9)	14(10.4)
42. on recreational activities (party, theater, etc.)	18(31.1)	20(26.3)	38(28.3)

Needs for financial support

In general, parents' needs for financial support mainly concern their child's therapy in occupational therapies, speech therapies, etc. (85.1%), their daily basic needs (43.3%) and their recreational activities (28.3%). (4.5%).

Table7. Family needs for a well-functioning family. Frequency and percentages in rapports

<i>About your family, you need help...</i>	<i>Fathers (N =58) f (%)</i>	<i>Mothers (N = 76) f (%)</i>	<i>Total (N = 134) f (%)</i>
43. discussing and resolving various problems	26(44.8)	62(81.5)	88(65.7)
44. supporting each other another in difficult times	32(55.2)	58(76.3)	90(67.2)
45. sharing house responsibilities to everyone individually	22(37.8)	30(39.5)	52(38.8)
46. planning the your jobs and you getting joint decisions	16(27.5)	12(15.8)	28(20.9)

Regarding family's function, some differences were recorded between parents. More specifically, fathers expressed needs for help in supporting each other in cases of difficult times -55.2% - followed by their need to discuss and solve various issues-44.8%. Conversely, for mothers, the need for discussion and problem solving prevails in 81.5%, followed by the support of each other in difficulties -76.3% -. Regarding other needs there is no difference between men and women.

Table 8. Averages of the percentages of petitions in the declarations - Categories of Needs

<i>Needs Categories</i>	<i>Fathers (N=58) f (%)</i>	<i>Mothers (N = 76) f (%)</i>	<i>Total (N = 134) f (%)</i>
1. More information	79.3	90.5	85.1
2. Social support	62.8	72.1	67.5
3. Explanation of your child's difficulties to people of your environment	32.4	39.7	36.3
4. Search for assistives services	51.3	57.2	54.3
5. Financial support	29.8	33.4	31.9
6. Well-functioning family	33.6	39.2	36.8

Parental needs by category

As shown in Table 8, the average of all parents expressed needs for more information -85.1% - and social support at a rate of 67.5%. The review of the table above shows that in both of the aforementioned variables mothers showed higher percentages compared to fathers (90.5% and 79.3% and 72.1% and 62.8% respectively). The total needs were followed by the search for support services (54.3%), the proper functioning of the family (36.8%) and lastly the financial support (31.9%).

Relationships between parental needs and demographic variables

Our goal was to investigate the relationship between parental needs and demographic variables such as gender, age, educational level, and occupational status of the sample. To examine the statistical significance we used the statistical criterion χ^2 . The analysis of the data revealed a statistically significant relationship between gender and four sub-needs. More detailed than the information category, the need for more information to handle child's behavior ($\chi^2 = 6.23$, $p = .036$) and the need to teach new skills ($\chi^2 = 7.76$, $p = .006$). From the category of well-functioning family, the need to discuss and solve various problems ($\chi^2 = 5.26$, $p = .007$) and the support of the couple during difficult times ($\chi^2 = 4.69$, $p = .042$).

In all cases, mothers were more likely to state specific needs compared with fathers. Regarding the age variable and the expressed needs, statistically significant relationships emerged in two sub-needs. Specifically in the category of social support and the need for friends to talk ($\chi^2 = 6.23$, $p = 0.041$) as well as in the planning of tasks to make joint decisions ($\chi^2 = 5.31$, $p = .015$).

Regarding the age variable and the expressed needs, statistically significant relationships emerged in two sub-needs. Specifically in the category of social support and the need for friends to talk ($\chi^2 = 6.23$, $p = 0.041$) as well as in the planning of tasks to make joint decisions ($\chi^2 = 5.31$, $p = .015$). Older parents (aged 51-62) were more likely to state specific needs compared with younger parents (aged 37-50).

In terms of educational level and parental needs, two statistically significant relationships were found which concern the category of family functioning. More specifically, the need to discuss and solve various problems ($\chi^2 = 7.13$, $p = .007$) as well as scheduling tasks to make decisions together ($\chi^2 = 9.18$, $p = .005$). Higher education people were more likely to state these needs compared with high school graduates.

Finally, in terms of occupational status and needs of the sample, a statistically significant relationship was identified in two sub-needs. Specifically, from the category of well-functioning family, the need to discuss and solve various problems ($x^2 = 6.35$, $p = .001$) as well as the planning of tasks so that you can make decisions together ($x^2 = 4.16$, $p = .0043$). Employees were more likely to report needs than those who did housework or were looking for job position.

The effect of demographic characteristics on the number of needs

To study the effect of demographic characteristics of both parents and children on the number of needs per category, as derived from the sum of the positive reports, the t-test was applied for independent samples. Only in one category was a statistically significant relationship found and this concerned age. Older parents reported more needs compared with younger parents. In particular, the average number of needs for social support stated by older parents (M.O.9.21) was significantly higher [$t(29) = 2.35$, $p = 0.014$ compared with that of younger parents (M.O. = 3.89).

Nevertheless in terms of the effect of children's demographic variables on the number of needs, it was recorded that the parents of younger children stated fewer needs on average compared to those who had older children. Only in one category the difference found to be statistically significant and related to ancillary services. More specifically, the average need for support services of the parents of older people was significantly higher [$t(29) = 2.69$, $p = .006$ than that of parents with younger children (M.O = 3.36).

DISCUSSION

The present study aimed to identify the needs of the parents having a child with ID and to investigate their relationship with demographic characteristics. Our research results showed that parents expressed needs for more information, social support, and support services, findings similar to other researches²². According to Verma⁹ parents' needs varied according to the age and the gender of the child. Severity of ID has less impact on the nature of parental needs. The needs of mothers and fathers can be different.

Regarding the category of needs for more information, parents asked for information related to sex education and handling issues related to adolescence, issues related to the future of their children as well as the services available for the future. One of the factors that increases the anxiety of parents is the uncertainty about the future of their children²³. Parental responsibility seems to correspond with the kind of support received²⁴. Support is long-term, ongoing tailored to individual needs²⁵. Research²⁶ results indicated that the families have language and speech support needs for their children and information needs for themselves, and that they are mostly satisfied with their partnerships with the professionals and their Family Quality Of Life. Results also indicated that their degree of satisfaction with the support was a good predictor of FQOL and their ratings of partnership quality was a key factor interceding on this effect. Severity of ID had less impact on the nature of parental needs. The needs of mothers and fathers can be different⁹.

The social support category is dominated by the need for both parents to have their own friends due to deficits in individual and social skills, and for the various professionals to speak to them in a way that is understandable to them, reflecting the lack of adequate cooperation and

negotiation between these two sides. Research²⁷ showed that mothers revealed that their children with disabilities had insufficient access to services and support related to health care, transportation and recreation. Family quality of life was negatively affected by financial restrictions and social interaction difficulties. Caring a child with disabilities seemed to be centered on the mother and religious coping appeared as a common psychological adjustment strategy.

Almost half of the parents seek help in order to explain their child's behavior and difficulties to his siblings. According to Burke²⁸ parents may have this need as they feel neglected by their other children and such behavior seems to have a negative effect on family cohesion. In addition^{29,30}, they seem to want to improve their parental role so that siblings do not lead to isolation or other negative reactions or behaviors.

In the category of support services, most parents find it difficult to find the most suitable school for their child. With respect to support systems, research³¹ found that parents indicated that they primarily rely on their child's school, their spouse, and their extended families. Minor differences were found between mothers and fathers (with mothers perceiving greater level of needs than fathers), and families of children with autism spectrum disorder tended to report greater needs for information and supports than parents of children with ID.

Most of the money is spent by the parents for the child's therapy sessions as it is possible that some of the child's treatments are not fully covered by the insurance funds.

In the category of the proper functioning of the family, the needs for mutual support and in the solution of various family problems are expressed. In gender responses, fathers expressed a need for help in supporting each other in difficult times, while mothers are in need of discussion and problem solving. Probably such a finding is related to the different degree of involvement of parents in family matters.

Needs related to mutual support, discussion and solution of various problems, division of responsibilities and joint decision-making³². These findings are related to family functioning when a member of it has special needs. According to Hartley³³ mothers had a higher number of important support needs and higher proportion of important support needs that are unmet than fathers.

Regarding the effect of demographic variables, it was found that older parents reported more needs compared to younger parents and in addition parents of younger children reported fewer needs than those with older children. Research results indicated³⁴ higher stress and needs of mothers compared to fathers regarding the overall parent-child relationship and the child's individual characteristics.

The present study confirms the need to treat parents of children with ID as an important aspect of the issue of studying the family of people with disabilities. The needs of families and each individual member are real even when they are not honestly externalized. In addition, these needs are not related to individuals but are related to the family system. An important parameter is the different dimension that needs acquire in different levels of the family system. In particular, it is easier to meet the needs of the family micro-system than the needs of the medium or macro-system.

The study of family needs will help to draw conclusions about the variables that are involved in the formation of needs which, when not met, direct parental behavior into practices that erode family cohesion. Cross-cultural findings will help in understanding the process of meeting those needs, with ultimately help in designing appropriate interventions. Family interventions should focus on the needs of mothers and fathers separately.

Our research has some limitations and the main ones are the following:

1. The statistical procedure that was implemented had the logic of the relevance approach without looking for a cause-effect relationships. Therefore, our findings cannot be generalized as they are an indication that needs further systematic investigation and confirmation.
2. Systematic assessment of family needs requires a long-term research effort. Our research study assessed the views of the subjects in a specific period of time.
3. Some variables were not included in the survey. Variables such as Total Quality of Life of the family, self-efficacy and perception of control and family climate were not examined.

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