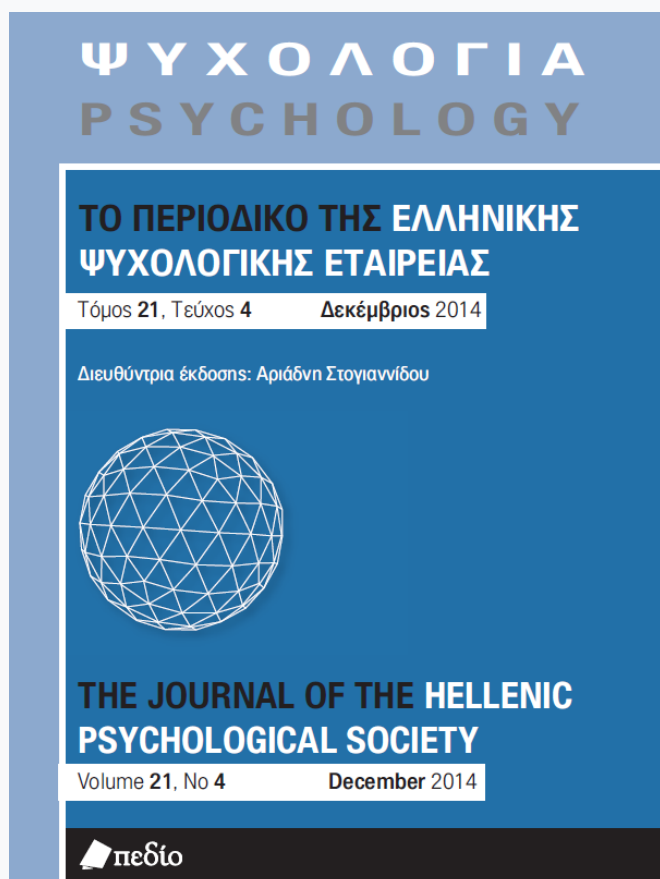


Psychology: the Journal of the Hellenic Psychological Society

Vol 21, No 4 (2014)



Intellectual disability and mothers' stressors: A Greek Paradigm

Κωνσταντίνος Βουγιούκας, Μαρία Τζουριάδου,
Γεώργιος Μενεξές, Μαρία Γκέκα, Λητώ - Ελένη
Μιχαλοπούλου

doi: [10.12681/psy_hps.23510](https://doi.org/10.12681/psy_hps.23510)

Copyright © 2017, Κωνσταντίνος Βουγιούκας, Μαρία Τζουριάδου,
Γεώργιος Μενεξές, Μαρία Γκέκα, Λητώ - Ελένη Μιχαλοπούλου



This work is licensed under a [Creative Commons Attribution-ShareAlike 4.0](https://creativecommons.org/licenses/by-sa/4.0/).

To cite this article:

Βουγιούκας Κ., Τζουριάδου Μ., Μενεξές Γ., Γκέκα Μ., & Μιχαλοπούλου Λ. -. Ε. (2017). Intellectual disability and mothers' stressors: A Greek Paradigm. *Psychology: The Journal of the Hellenic Psychological Society*, 21(4), 421–436. https://doi.org/10.12681/psy_hps.23510

Intellectual disability and mothers' stressors: A Greek Paradigm

CONSTANTINOS VOUYOUKAS¹, MARIA TZOURIADOU², GEORGIOS MENEXES³

MARIA GEKA⁴ & LITO-ELENI MICHALOPOULOU⁵

ABSTRACT

Ongoing research has demonstrated higher levels of stress for parents of children with intellectual disabilities than in parents of typically developed children. Three major source domains of parental stress include comorbid conditions, parental characteristics and parents' life situations. The aim of this study was the investigation of Greek mothers' perceptions of the characteristics of their intellectually disabled children and their life situations as stressors. The research was carried out in Rhodes, Greece. The study sample consisted of fifty-nine mothers of children diagnosed with moderate intellectual disabilities with and without comorbid conditions. Interviews were used to collect the data. Main findings were that stress varies among mothers of children with intellectual disabilities and that children comorbid conditions appear to be the most important maternal stress factor. Family support should be based on the partnership-empowerment model. Further research on family needs of children with intellectual disabilities is needed in Greece, so that children find partnership and support throughout their lives.

Keywords: Moderate intellectual disabilities, Mothers' stressors, Comorbid conditions, Family support.

1. Address: Faculty of Preschool Education Sciences, Department of Psychology and Special Education, Aristotle University of Thessaloniki. E-mail: costasv@nured.auth.gr, tel: +30 2310 991299

2. Address: Faculty of Preschool Education Sciences, Department of Psychology and Special Education, Aristotle University of Thessaloniki.

3. Address: School of Agriculture, Lab of Agronomy, Aristotle University of Thessaloniki

4. Address: Faculty of Preschool Education Sciences, Department of Psychology and Special Education, Aristotle University of Thessaloniki.

5. Address: School of Education, The Pennsylvania State University

1. Introduction

Intellectual disability is a developmental disorder characterized by significant limitations, both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disorder begins before the age of 18 (Whemeyer & Obremski, 2010). The interaction between severity codes and levels of support creates the profile of the intellectually disabled child. The more severe the disability of the child, the greater the need for support, which results in an extra parental burden (Schalock et al., 2007).

Intellectual disability is a condition and a source of pain and stress to many families. Studies have shown that parents of children with intellectual disabilities need to engage their children more than those parents with normally developed children (Westling, 1997) and they can easily be discouraged because of their children's failure to meet basic needs (Dervishali, 2013). This condition results in higher stress levels for parents of children with intellectual disabilities than for parents of typically developed children (Feldman, Hon & Walton-Allen, 1997).

According to Lazarus and Folkman (1984), parental stress can be broken down into four domains: (a) stressors, (i.e., any event or situational factor exceeding the individual's coping ability), (b) strain or the physical and emotional symptoms of a stressful event, (c) resources the individual utilizes to cope with the effects of the stressors and (d) coping strategies utilized by the individual to avoid or reduce the effects of stressors.

Abidin (1995) acknowledges three major source domains of parental stress: (a) the child's characteristics, which include mental and cognitive disabilities and comorbid conditions (e.g., attention deficit, epilepsy, autism, etc.) (Johnston, Hessler, Blasey et al. 2003), (b) parental characteristics, such as low self-esteem and a sense of incompetence (Johnson, 2000) and (c) stressful situations in the parents' lives that include depressing events, particularly for mothers, such as marital problems and the child's demands (Gallagher et al., 2008. McConachie, 1994). The interaction of the three

source domains of stressors affects the degree to which parents of children with intellectual disabilities experience stress (Cain & Combs, 2005).

Ever since the 1960s, researchers and clinical studies (Holroyd, 1974. Kazak, 1987) have investigated interparental stressors to a greater extent and the interaction between mother-child characteristics and extra familial factors to a lesser extent (Abidin, 1995. Cameron, Dobson & Day, 1991). Ongoing research has found that parenting intellectually disabled children is a stressful condition affected by a variety of sources, such as the child's physical and emotional dependence; the demand for special care; disappointments over the child's delayed skill development, particularly in the area of speech and language; and from a number of additional factors that place both the family's and the child's future at risk (Cramm & Nieboer, 2011. Saloviita, Italinna & Leinonen, 2003). Johnston, Hessler, Blasey et al. (2003) argue that the child's comorbid conditions are compellingly related to parental depression and despair. According to Davis and Carter (2008) and Sanders and Morgan (1997), parents of autistic children report higher stress and more adjustment problems than parents of children with Down syndrome, perhaps because children with autism exhibit more behavioural problems than children with Down syndrome. Abbeduto et al. (2004) provide research evidence that demonstrates that mothers of children with Down syndrome often fare better than do mothers of children with other forms of intellectual disabilities (e.g., autism and fragile X syndrome).

The intellectual disability and the problems associated with it affect parents' adaptive ability since they often feel responsible for their child's disability (Daire, Casado-Kehoe & Lin, 2005. Kerr & McIntosh, 2000). Thus, parents of children with intellectual disabilities can experience anxiety, fears, stigma, isolation, aggression, shame, guilt or even hostility towards and rejection of the disabled child (Emerson, 2003. Peterson & Mathieson, 2000. Walton, 1993. Wong et al., 2004). More particularly, the depression experienced by parents of children with intellectual disabilities may weaken their attempts to actively manage their child's behaviour and makes

them more passive (Hastings & Beck, 2004. Olsson & Hwang, 2001). Some studies of parents with children with Down syndrome have not found any depression or other signs of passive behaviour (Scott et al., 1997. Van Riper, Ryff & Pridham, 1992).

Hassall, Rose and McDonald (2005) argue that parental stress varies considerably among parents of children with intellectual disabilities and that these stress levels are associated with a wide range of variables. Several studies have found that the severity of a child's condition is associated with parental stress (Gupta, 2007. Minnes, 1988), whereas others have failed to find any similar associations (Beckman, 1983. Ferguson & Watt, 1980. Walker, Van Slyke & Newbrough, 1992). The child's age as a factor of parental stress is unclear. Some studies report that the stress is lower when the child is older (Khamis, 2007), while other studies state that older children appear to cause higher stress (Tunali & Power, 1993). Still other researchers report that there is no relationship between the child's age and parental stress (Johnston et al., 2003. Wulffaert, van Berckelaer-Onnes. Kroonenberg et al., 2009).

Overall, certain characteristics of the intellectual disability seem to play a more important role on parental stress, such as the child's communication skills and behavioural difficulties (Estes et al., 2009. Eyberg, Boggs & Rodriguez, 1992. Frey, Greenberg & Fewell, 1989. Friedrich, Wiltner & Cohen, 1985. Konstantareas & Homatidis, 1989. Neece, Green & Baker, 2012. Quine & Pahl, 1991). Padeliadou (1998) administered a questionnaire to Greek mothers of children with Down syndrome and found that mothers reported a higher degree of stress than mothers of non-disabled children. Konstantareas and Papageorgiou (2006) used the same questionnaire on Greek mothers of autistic children and found that the autistic children's level of functioning was not related to maternal stress.

To date, there has been a substantial amount of research concerning intellectual disabilities and on the psychological, educational and social traits of intellectually disabled children in Greece (e.g., Kartasidou et al., 2013. Vlachos, Stavroussi & Pisi-na, 2012). However, there has been limited re-

search on parents of children with intellectual disabilities and, specifically, on the variety of stressors experienced by mothers of children with intellectual disabilities.

The aims of this study were a) to investigate Greek mothers' perceptions of the characteristics of their intellectually disabled children and their life situations as stressors and b) to find a typology of mothers relative to their previously mentioned perceptions in relation to their children's comorbid conditions.

2. Method

Participants

The research was conducted on the Greek island of Rhodes, a medium-sized Greek province with a population of 115,290 with both urban and rural characteristics (ELSTAT, 2011). Rhodes' socio-cultural characteristics can be considered representative of the Greek culture, which include strong family and social bonds (Georgas et al., 1997) and an emphasis on the role of society and social criticism (Argyraoulis & Zafiropoulou, 2003).

Mothers were selected as the target group because they bear most of the burden of childrearing in Greek society (Georgas, 1988. Padeliadou, 1998). Mothers were located through 7 special schools, 1 hospital and 2 mental health centres operating in Rhodes. One hundred and fifty one mothers of children with intellectual disabilities were identified. Fifty eight mothers had children diagnosed with mild intellectual disabilities, 63 mothers had children diagnosed with moderate intellectual disabilities and 30 mothers had children diagnosed with severe intellectual disabilities. The mothers of children with moderate intellectual disabilities comprised the study sample. Moderate intellectual disability was chosen because the condition is detectable as early as birth (AAIDD, 2008. Ysseldyke, 1987) and is not confused with other disabilities (US Department of Education, 1995). In most cases it is associated with comorbid conditions (Luckasson et al. 2002) and requires extensive life support (Schalock et al., 2007). In the study sample, 59

out of the 63 mothers agreed to participate in the study. Thirty five mothers had children who received special education school services and 24 mothers had children who attended vocational facilities and special education workshops; 34 mothers had children between four and ten years of age, and 25 mothers had children between 11 and 18 years of age; 26 mothers had children diagnosed with moderate intellectual disabilities without comorbid conditions and 33 mothers had children diagnosed with moderate intellectual disabilities and comorbid conditions (attention deficit, epilepsy, emotional disorders, brain damage).

Measures

An interview guide (Turner, 2010) was developed by the authors to elicit the types of stressors felt by mothers of children with moderate intellectual disabilities, with or without comorbid conditions. The authors conducted a pilot test with the interview guide on eight (8) mothers. The interview guide questions were designed to discover the range of the mothers' responses regarding the stressors they experienced. Interviews began with a "grand tour" question, "What stressors do you feel regarding your children with intellectual disabilities?", followed by questions about the mothers' emotions for and expectations of their children with intellectual disabilities as well as information about and support for their children. After conducting the eight interviews, the authors reviewed the order, usefulness and the addition/deletion of questions. The interview guide was then adjusted accordingly, with only minor changes in the wording of the questions.

Based on Abidin's (1995) Parenting Stress Model, the interviews explored two axes of stressful factors for mothers. Axis 1 gives *child characteristics*, including all factors related to children with intellectual disabilities and Axis 2 gives the *situational mothers' life*, including all factors related to the mothers of children with intellectual disabilities (see Table 2). The interview questions had the same structure and order for all participant mothers. The use of specific interview questions en-

sured that the interviewees would not be side-tracked from the research goals or from the homogeneity of the interview.

Procedure

Data collection was initiated in February 2012 and completed in May 2013. The research was undertaken with the understanding and written consent of each participant after the researchers informed each mother about the research procedure. The interviews were home-based and each lasted approximately one (1) to one-and-a-half (1.5) hours. During the first stage, the authors audio-recorded the mothers' answers, transcribed the recorded interviews and filled in the protocols with the mothers' answers on the interview questions. During the second stage, the authors reviewed each transcript for completeness and accuracy and performed qualitative analysis on the mothers' answers by means of content analysis using multiple strategies, including searching the text for main ideas, listening to stories, putting themes together, identifying repetition among respondents, looking for opposing themes and searching for confirming and contradicting evidence of themes (Lingard, Albert & Levinson, 2008).

Statistical Analysis

Data were summarized by calculating absolute and relative frequencies (percentages). The multiple correspondence analysis (MCA) method was used to briefly explore the structure of interview questions and to function primarily as a pre-processing procedure prior to the application of hierarchical cluster analysis (HCA). MCA method is a multivariate method suitable for exploring the relations between cross-tabular categorical data and it can be regarded as an extension of the ordinary principal component analysis (PCA) suitable for analyzing the association between variables measured on nominal scale. Within the methodological frame of the MCA, an optimal score according to the MCA's significant factorial axis was computed for each mother (Michailidis & De Leeuw, 1998). A

detailed description and presentation of the MCA can be found in the research conducted by Greenacre (1993). These scores were entered as input to the HCA in order to find groups of mothers. A presentation of various clustering methods can be found in Everitt (1993). The squared Euclidean distance was used as a measure of dissimilarity between mothers and Ward's criterion was used for the formation of the mothers' groups (Hair & Black, 2000. Sharma, 1996). The contribution of each MCA's factorial axis in the cluster formation was evaluated by examining the magnitude and the statistical significance of the corresponding R^2 coefficients of determination estimated by the application of two one-way ANOVAs. Cluster membership was used as the independent variable and the two MCA factorial scores were used as the dependents (Michos et al., 2012. Taxidis et al., 2015). The value of R^2 indicates the percentage of variance of the examined variable accounted by the differences between the clusters (Sharma, 1996). The R^2 is numerically equivalent to the eta-squared (h^2) index, a measure of the cluster's membership-effect size (Cortina & Nouri, 2000). High and statistically significant values of the R^2 coefficients could be considered as indicators of the validity (i.e., goodness of a clustering structure without respect to external information) of a cluster solution (Halkidi, Batsidakis & Vazirgiannis, 2001). The statistical significance of the resulting cluster solution was tested with the upper-tailed test (Mojena & Wishart, 1980). The results for this test were obtained by using Clustan software, v.5.27. The input-order stability of the resulting cluster solution was tested and verified by applying a bootstrap methodology proposed by Spaans and Van der Kloot (2004), which was implemented by the PermuCLUSTER v.1.0 software (an SPSS add-in). A series of χ^2 tests were performed for testing the differences of the mothers' groups relative to their answers to the interview questions. Cramer's V coefficient of association was calculated and used supportively to determine the relative contribution of each question to the groups' differentiation (Menexes & Angelopoulos, 2008). The observed significance level (p -value) of the χ^2 tests was estimated using the Monte Carlo

simulation method and based on 10,000 re-sampling circles (Mehta & Patel, 1996). This approach leads to valid inferential conclusions, even in cases where the methodological presuppositions of the statistical test employed are not satisfied (e.g., large samples, random samples, independent observations, symmetrical distributions and an absence of outliers). Main statistical analyses were performed using SPSS v.15.0, enhanced with the Categories module for the implementation of the MCA method and Exact Tests for the Monte Carlo simulation. The significance level in all hypothesis testing procedures was predetermined at $p < 0.05$.

3. Findings and discussion

MCA revealed two significant factorial axes that explained the 60.1% of total inertia (variance) of the generalised contingency table (Burt table), which cross-tabulated pair-wise the answers to the questions Q2 - Q14. Preliminary analyses (MCA and a series of χ^2 tests) showed that "child's age" (Q1) was not significantly associated with the other variables under study. The first factorial axis, F1, explained the 33.7% of total inertia (Cronbach's $\alpha = 0.74$). The second axis, F2, explained the 26.4% (Cronbach's $\alpha = 0.73$). Based on the analytical results of the MCA (contribution indices-Ctr), the interview questions that contributed most to the construction of factorial axis F1 were the following: Q7: "mother's emotions about state support for the provided intervention" (Ctr=193), Q13: "who first diagnosed the child" (Ctr=83) and Q10: "mother's satisfaction level regarding the help she provides to the child" (Ctr=76). Questions Q4: "state participation in the intervention provided to the child" (Ctr=146), Q8: "what makes the mother tired" (Ctr=132), Q3: "sources of information the mother had about the child's condition" (Ctr=114), Q6: "mother's expectations of the child's progress" (Ctr=109) and Q11: "mother's opinion about the factors that contribute to the child's effective education" (Ctr=98), contributed mainly to the construction of the second axis, F2. Question Q2: "child's comorbid conditions" contributed moder-

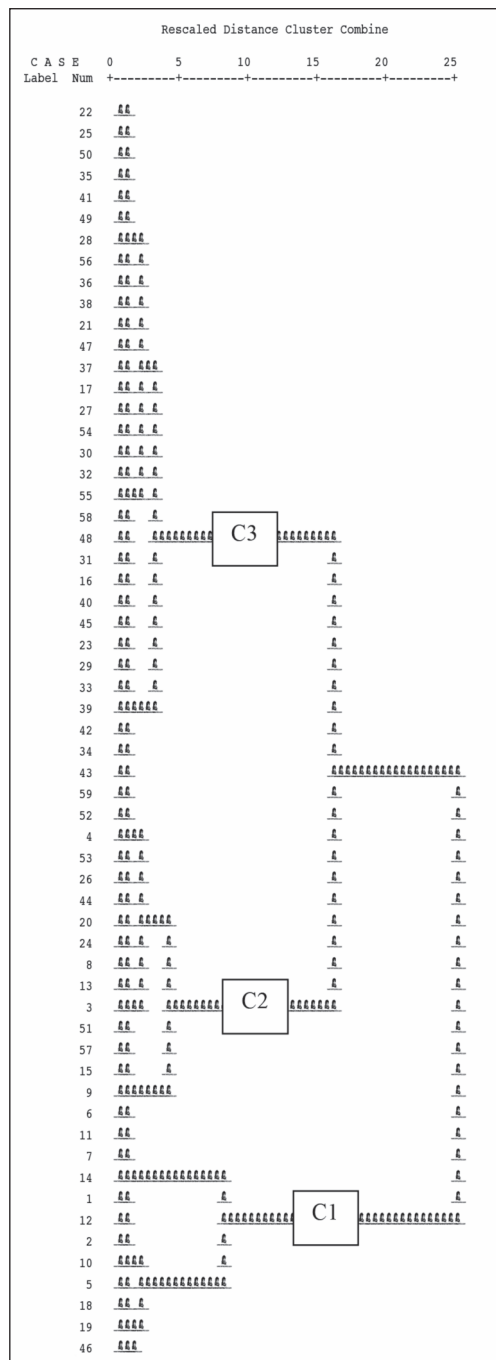


Figure 1
Hierarchical Cluster Analysis (HCA)
dendrogram of mothers' groups

ately to both factorial axes (Ctr on F1=54, Ctr on F2=46). This can be attributed to the fact that moderate intellectual disabilities are some of the most serious and stigmatised disabilities (AAIDD, 2008).

A basic distinction noted between the two MCA factorial axes is that the first axis was formulated by three questions, all of which deal with the situations in the mothers' lives, while the second axis was formulated by five questions, three of which deal with child characteristics.

By applying MCA, an optimal score for each mother was calculated on both factorial axes. Based on these scores, the HCA was performed in order to form groups of mothers. The HCA dendrogram (Figure 1) demonstrated that mothers could be classified into three groups. The upper-tailed rule showed that the three-cluster solution is statistically significant ($t=26.63$, $df=57$, $p<0.001$). The R^2 coefficients for MCA's axes F1 and F2 were estimated at 0.692 ($p<0.001$) and 0.520 ($p<0.001$), respectively. Twelve mothers (20.3% of the study sample) comprised the first group (C1), 16 mothers (27.1% of the study sample) were in the second group (C2), and 31 mothers (52.6% of the study sample) made up the third group (C3). This finding argues for stress variation among mothers of children with intellectual disabilities (Hassall et al., 2005).

A series of χ^2 tests of independence between the mothers' group membership and the 13 interview questions (Table 1) showed that mothers' grouping was mainly affected by questions: Q2: "child's comorbid conditions", Q4: "state participation in the intervention provided to the child", Q6: "mother's expectations of the child's progress", Q11: "mother's opinion about the factors that contribute to the child's effective education", Q8: "what makes the mother tired" and Q7: "mother's emotions about the state support to the provided intervention". The magnitude of the corresponding Cramer's V coefficients of association ($^30.450$) served as the criterion to highlight the questions that contributed most to mothers' separation. Questions Q5: "the broader family and friend environment support to the difficulties the child faces" and Q14: "mother's emotions at the first an-

Table 1
Significance of χ^2 tests and the corresponding Cramer's V coefficients for testing the association between mothers' group membership and their answers to questions Q2-Q14

| Questions | χ^2 test p-value | Cramer's V |
|-----------|-----------------------|------------|
| Q2 | <0.001 | 0.516 |
| Q3 | 0.002 | 0.445 |
| Q4 | <0.001 | 0.514 |
| Q5 | 0.323 ns | 0.281 ns |
| Q6 | <0.001 | 0.514 |
| Q7 | <0.001 | 0.450 |
| Q8 | <0.001 | 0.481 |
| Q9 | 0.049 | 0.356 |
| Q10 | 0.003 | 0.381 |
| Q11 | <0.001 | 0.483 |
| Q12 | 0.007 | 0.368 |
| Q13 | 0.004 | 0.359 |
| Q14 | 0.324 ns | 0.248 ns |

nouncement of the child's condition" did not have a statistically significant contribution to the differentiation of the mothers' groups.

What follows is a description of the three groups of mothers relative to their answers to the interview questions (Table 2). It is interesting that in the analysis (Diagram 1) based on the mothers' group profile according to child's comorbid conditions, group C1 consisted of mothers whose children were diagnosed with moderate intellectual disabilities with comorbid conditions (100%), group C2 consisted of mothers whose children were mostly diagnosed with moderate intellectual disabilities with no comorbid conditions (75%) and group C3 was a mixed group consisting of children diagnosed with moderate intellectual disabilities, 54.8% of whom had comorbid conditions and 45.2% did not.

Fifty percent of the answers given by mothers in the C1 group concerned the stress caused by the personal quest for information regarding the child's condition and 25% of the answers referred to feelings of anxiety, disappointment and guilt they

felt on the announcement of the child's disability. For 50% of the mothers in this group, the child's cognitive characteristics and health comorbid conditions caused a stressful situation, while for 41.7% of the mothers, stress was caused by insufficient access to community services. Fifty percent of the mothers in this group answered that they had support only from the immediate family and 41.1% of the mothers seemed concerned about the child's future after their death. A distinct characteristic of this maternal group, which most likely reflects the mothers' conflicting emotions and thoughts, was that their answers to the question about the provided help were distributed equally between "satisfactory" (33.3%), and "not satisfactory" (33.3%), while an equal percentage (33.3%) avoided answering the repeated questions and remained silent. Significantly, 33.3% avoided answering the question, "what makes you tired", 58.3% did not answer the question about the support they received regarding the provided intervention to the child and 66.7% avoided commenting on whether the education their children received was effective

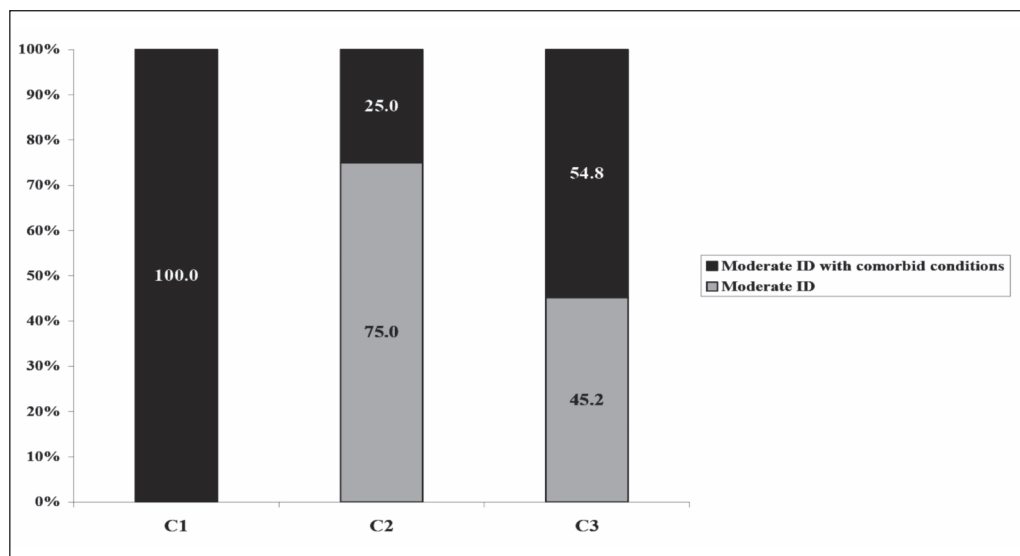


Diagram 1
Mothers' groups profiles relative to children's comorbid conditions

or not. It should be noted that the children of this group had been placed in special education settings as early as the beginning of their schooling and they had never received a conventional education. Instead, they were trained in basic life skills (e.g., how to get dressed). For the mothers, this kind of schooling was not considered a typical education but mere training in basic skills.

The stressful conditions for the mothers in the C2 group mainly concerned their children's education. More particularly, the mother's expectations caused stress to 81.3% of this group, the child's school progress was stressful to 43.8%, and the provided interventions caused stress to 62.5% of the mothers. Regarding the first announcement and diagnosis of the child's condition, 68.8% of the mothers in the second group answered that they were not satisfied and 75% said the only social support they received came only from the immediate family. As to what they themselves offered to their children, 62.5% stated that they were not satisfied and claimed they could have done more, particularly with regard to the child's education. Mothers in this group also seemed to share the same

conflicting emotions and thoughts as mothers in the first group upon the first announcement of the child's condition because 31.3% answered that they had felt disappointment, anger and guilt; 31.3% felt disappointment, anger, guilt and stress; and 25% remained silent, giving no answer. In this group, 75% had children with no comorbid conditions, which may account for the fact that they emphasised the child's education and the provided treatment services, expecting the child to be educated alongside ordinary children. These mothers seemed to have accepted the cognitive disabilities of their children and insisted on emphasising the services provided by general education. The findings could be explained by the fact that Greek parents generally place great importance and value on education (Saiti & Mitrosili, 2005).

As for the mothers in the C3 group, 71% said the cognitive characteristics of their children and their health problems caused them great stress. A high percentage of mothers (58.1%) attributed stress to issues relating to their expectations of the child's independent living, while an almost equally high percentage (45.2%) had fears about the

Table 2
Mothers' group profiles according to their answers (%) to interview questions

| Questions | Answers | Mother groups | | |
|--|---|---------------|-------|-------|
| | | C1 | C2 | C3 |
| Axis 1: child characteristics | | | | |
| Q1: Child's age | | | | |
| | 4-10 yrs | 66,7% | 62,5% | 51,6% |
| | 11-18 yrs | 33,3% | 37,5% | 48,4% |
| Q2: Child's comorbid conditions | | | | |
| | Moderate ID without comorbid conditions | 0.0% | 75.0% | 45.2% |
| | Moderate ID with comorbid conditions | 100.0% | 25.0% | 54.8% |
| Q6: Mother's expectations of the child's progress | | | | |
| | Independent living | 41.7% | 18.8% | 58.1% |
| | Better education | 25.0% | 81.3% | 19.4% |
| None | 8.3% | 0.0% | 22.6% | |
| | Independent living and better education | 25.0% | 0.0% | 0.0% |
| Q8: What makes the mother tired | | | | |
| | Child characteristics and health problems | 50.0% | 43.8% | 71.0% |
| | Homework, school issues | 0.0% | 31.3% | 16.1% |
| | Nothing | 0.0% | 12.5% | 12.9% |
| | Family relations | 16.7% | 12.5% | 0.0% |
| | No answer | 33.3% | 0.0% | 0.0% |
| Q9: Mother's fears regarding the future of the child | | | | |
| | Parents' death | 41.7% | 25.0% | 25.8% |
| | Fears regarding school progress | 8.3% | 43.8% | 12.9% |
| | Fears regarding mental health | 16.7% | 25.0% | 45.2% |
| | Nothing | 25.0% | 6.3% | 16.1% |
| | No answer | 8.3% | 0.0% | 0.0% |
| Q11: Mother's opinion about the factors that contribute to the child's effective education | | | | |
| | Encouragement and guidance | 16.7% | 6.3% | 35.5% |
| | Co-operation with the school and individualized support | 16.7% | 31.3% | 38.7% |
| | Encouragement and guidance, co-operation with the school and individualized support | 0.0% | 50.0% | 9.7% |
| | No answer | 66.7% | 12.5% | 16.1% |

| | | | | |
|--|-------|-------|-------|--|
| <i>Q12: Mother's emotions during pregnancy</i> | | | | |
| Anxiety and fear | 16.7% | 25.0% | 19.4% | |
| Sorrow | 0.0% | 6.3% | 0.0% | |
| Anxiety, fear & sorrow | 33.3% | 12.5% | 64.5% | |
| No answer | 50.0% | 56.3% | 16.1% | |
| <i>Q14: Mother's emotions at the first announcement of the child's condition</i> | | | | |
| Anger | 25.0% | 12.5% | 16.1% | |
| Disappointment, sorrow and guilt | 16.7% | 31.3% | 54.8% | |
| Anger, disappointment, sorrow and guilt | 33.3% | 31.3% | 19.4% | |
| No answer | 25% | 25% | 9.7% | |
| <i>Axis 2: situational mothers' life</i> | | | | |
| <i>Q3: Sources of information mother had about the child's condition</i> | | | | |
| Other parents and personal quest | 50.0% | 31.3% | 22.6% | |
| Professionals | 16.7% | 18.8% | 51.6% | |
| None | 33.3% | 0.0% | 12.9% | |
| Personal quest and professionals | 0.0% | 43.8% | 12.9% | |
| No answer | 0.0% | 6.3% | 0.0% | |
| <i>Q4: State participation in the intervention provided to the child</i> | | | | |
| Advocacy services | 8.3% | 50.0% | 25.8% | |
| Financial support | 41.7% | 0.0% | 3.2% | |
| None | 25.0% | 31.3% | 35.5% | |
| Advocacy services and financial support | 16.7% | 0.0% | 35.5% | |
| No answer | 8.3% | 18.8% | 0.0% | |
| <i>Q5: The broader family and friend environment support to the difficulties the child faces</i> | | | | |
| Family | 50.0% | 75.0% | 61.3% | |
| Extended family and friend environment | 8.3% | 0.0% | 6.5% | |
| Nobody | 16.7% | 25.0% | 6.5% | |
| Family, extended family and friend environment | 25.0% | 0.0% | 22.6% | |
| No answer | 0.0% | 0.0% | 3.2% | |
| <i>Q7: Mother's emotions about the state support to the provided intervention</i> | | | | |
| Disappointment and anger | 16.7% | 62.5% | 67.7% | |
| Satisfaction | 25.0% | 25.0% | 32.3% | |
| No answer | 58.3% | 12.5% | 0.0% | |
| <i>Q10: Mother's satisfaction level regarding the help she provides to the child</i> | | | | |
| Yes | 33.3% | 37.5% | 41.9% | |
| No, I could provide more | 33.3% | 62.5% | 58.1% | |
| No answer | 33.3% | 0.0% | 0.0% | |

child's mental health. In looking at the type of support these mothers received, the majority (51.6%) answered that they received professional support (advocacy service), while 61.3% answered that the social support they received came only from close family. Over two-thirds (67.7%) of the interviewees said they were completely dissatisfied with the state support for their children, while 58.1% said they were not satisfied with the provisions they themselves were offering to their children. This group was comprised mothers of children who had a greater percentage of comorbid conditions (54.8%), which may explain the large number of stressors related to the child's physical and mental health problems. The main characteristic of the third group was that mothers appeared to be highly affected by the situations they experienced regardless of the child's comorbid conditions.

The three groups were not statistically significantly different relative to the distribution of children's age ($p=0.636$). Based on the HCA dendrogram (Figure 1) and mothers' group profiles according to children's comorbid conditions (Diagram 1), evidence suggests that groups C2 and C3 showed greater proximity, while group C1 was more distinctive. This can be attributed to the fact that group C1 consisted of children whose conditions were more severe due to their comorbid conditions as compared to groups C2 and C3 (Johnston et al, 2003).

4. Limitations

Convenience sampling was used, in which participant mothers were selected from available areas and populations. It is not clear whether the study results can be generalized to the wider population because of the small sample size. Even so, this study can be considered as a valuable tool for future research.

5. Conclusions

The current findings highlight the significant

role of comorbid conditions on maternal stress. Since comorbid conditions involve the presence of more than one disability that co-exists with an intellectual disability, the source of mothers' stressors seems to concern not the intellectual disability itself but the comorbid conditions. Additionally, the emergence of three different groups of mothers with children with intellectual disabilities and the stressors they felt argues for the variations of stress among families. It appears that stress-inducing conditions differ among the families of children with intellectual disabilities and may vary according to a range of different characteristics (child, family and community), which parents may or may not find stressful. Current findings also show that the age of the child is not a significant stressor for the mother. This finding is in accordance with the research of Johnston et al. (2003) and Wulffaert et al. (2009) and does not relate to research findings of Khamis (2007) and Tunali and Power (1993).

The study demonstrated that the stressors Greek mothers experienced concerned the child's characteristics and life situations. As to their own feelings, mothers of children with intellectual disabilities with comorbid conditions spoke only about fear, stress and anger regarding their children and made no reference to personal feelings that might have arisen during childrearing or to relationships with husbands, other family members and the extended family. They also expressed fears about the physical and mental health of their children, as well their future after the death of the mothers. For mothers of children with intellectual disabilities without comorbid conditions, the most significant stressful factors were the provisions for better education and their expectations for the child's achievement in school.

Even though in recent years the partnership-empowerment model has been adopted in Greece to support the families of children with intellectual disabilities (Law 2817/2000), it seems that professionals continue to control the parent-professional relationship rather than consulting parents in a negotiated decision-making process. Interdisciplinary groups are largely staffed by school teachers who focus mainly on the assessment and treatment of

children's school difficulties and do not support the broader needs of children and families (Tzouriadou, Kontopoulou-Kokkinaki & Psinos, 2008). Continued research on the family needs of children with intellectual disabilities is needed so that Greek children will be able to receive partnership and support throughout their lives.

References

- AAIDD, (2008). *American Association on Intellectual and Developmental Disabilities*.
- Abbeduto, L., Seltzer, M.M., Shattuck, P., Krauss, M.W., Orsmond, G. & Murphy, M.M. (2004). Psychological well-being and coping in mothers of youths with autism, down syndrome, or fragile X syndrome. *American Journal on Mental Retardation* 109, 237-254.
- Abidin, R.R. (1995). *Parenting Stress Index*. Odessa: Psychology Press.
- Argyraoulis, E. & Zafiropoulou, M. (2003). Self-esteem of Greek mothers of children with intellectual disabilities. *International Journal of Disability, Development and Education*, 50, 181-195.
- Beckman, P.J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. *American Journal of Mental Deficiency*, 88, 150-156.
- Cain, D.S. & Combs-Orme, T. (2005). Family structure effects on parenting stress and practices in the African American Family. *Journal of Sociology and Social Welfare*, 32, 19-40.
- Cameron, S.J., Dobson, L.A. & Day, D.M. (1991). Stress in parents of developmentally delayed and non-delayed preschool children. *Canada's Mental Health*, 39, 13-17.
- Cortina, J. & Nouri, H. (2000). *Effect Size for ANOVA Designs*. Thousand Oaks: Sage Publications, Inc.
- Cramm, J.M. & Nieboer, A.P. (2011). Psychological well-being of caregivers of children with intellectual disabilities: using parental stress as a mediating factor. *Journal of Intellectual Disabilities*, 15, 101-113.
- Daire, A.P., Casado-Kehoe, M. & Lin, C.H. (2005). Coping responses and emotional distress in fathers of children with special needs and "redreaming" as a creative intervention. *Journal of Creativity in Mental Health*, 1, 253-271.
- Davis, N.O. & Carter, A.S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38, 1278-1291.
- Dervishaliaj, E. (2013). Parental stress in families of children with disabilities: a literature review. *Journal of Educational and Social Research*, 3, 579-584.
- ELSTAT (2011). *Greek National Statistics*. Greek Population Census 2011.
- Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47, 385-399.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou X-H. & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay, *Autism*, 13, 375-387.
- Everitt, B. (1993). *Cluster Analysis*. London: Edward Arnold.
- Eyberg, S., Boggs, S.R. & Rodriguez, C.M. (1992). Relationships between maternal parenting stress and child disruptive behavior. *Child and Family Behavior Therapy*, 14, 1-9.
- Feldman, M.A., Hon M.L. & Walton-Allen, N. (1997). Stress in mothers with intellectual disabilities. *Journal of Child and Family Studies*, 6, 471-485.
- Ferguson, N. & Watt, J. (1980). The mothers of children with special education needs. *Scottish Educational Review*, 12, 21-31.
- Frey, K.S., Greenberg, M.T. & Fewell, R.R. (1989). Stress and coping among parents of handicapped children: a multi-dimensional approach. *American Journal on Mental Retardation*, 94, 240-249.
- Friedrich, W.N., Wiltner, L.T. & Cohen, D.S. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency*, 90, 130-139.
- Gallagher, S., Phillips, A.C., Oliver, C. & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, 33, 1129-1136.
- Georgas, J., Christakopoulou, S., Poortinga, Y., Goodwin, R., Angleitner, A. & Charalambous, N. (1997). The relationship of family bonds to family structure

- and function across cultures. *Journal of Cross-Cultural Psychology*, 28, 303-319.
- Georgas, J., (1988). An ecological and social cross-cultural model: The case of Greece. In: J.W. Berry, S. H. Irvine & E.B Hunt (Eds.). *Indigenous Cognition: Functioning in Cultural Context* (pp. 105-123). Dordrecht: Martinus Nijhoff.
- Greenacre, M.J. (1993). *Correspondence Analysis in Practice*. London: Academic Press.
- Gupta, V. B. (2007). Comparison of parenting stress in different developmental disabilities. *Journal of Developmental and Physical Disabilities*, 19, 417-425.
- Hair, J. & Black, W. (2000). Cluster Analysis. In L. Grimm and P. Yarnold (Eds.), *Reading and Understanding More Multivariate Statistics* (pp. 147-205). Washington: DC: American Psychological Association.
- Halkidi, M., Batistakis, Y. and Vazirgiannis, M. (2001). On clustering validation techniques. *Journal of intelligent Information Systems*, 17, 107-145.
- Hassall, R., Rose, J. & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49, 405-418.
- Hastings, R.P. & Beck, A. (2004). Practitioner review: stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry*, 45, 1338-1349.
- Holroyd, J. (1974). The questionnaire on resources and stress: an instrument to measure family response to a handicapped family member. *Journal of Community Psychology*, 2, 92-94.
- Johnson, B.S. (2000). Mothers' perceptions of parenting children with disabilities. *The American Journal of Maternal/Child Nursing*, 25, 127-132.
- Johnston, C., Hessel, D., Blasey, C., Eliez, S, Erba, H., Dyer-Friedman, J. et al. (2003). Factors associated with parenting stress in mothers of children with fragile X syndrome. *Developmental and Behavioral Pediatrics*, 24, 267-275.
- Kartasidou, L., Dimitriadou, I., Pavlidou, E., & Varsamis, P. (2013). Independent living and interpersonal relations of individuals with intellectual disability: the perspective of support staff in Greece. *The International Journal of Learner Diversity and Identities*, 19, 59-73.
- Kazak, A.E. (1987). Families with disabled children: stress and social networks in three samples. *Journal of Abnormal Child Psychology*, 15, 137-146.
- Kerr, S.M. & McIntosh, J.B. (2000). Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: Care, Health and Development*, 26, 309-322.
- Khamis, V. (2007). Psychological distress among parents of children with mental retardation in the United Arab Emirates. *Social Science & Medicine*, 64, 850-857.
- Konstantareas, M.M. & Homatidis S. (1989). Parental perception of learning-disabled children's adjustment problems and related stress. *Journal of Abnormal Child Psychology*, 17, 177-186.
- Konstantareas, M.M., Papageorgiou, V. (2006). Effects of temperament, symptom severity and level of functioning on maternal stress in Greek children and youth with ASD. *Autism*, 10, 593-607.
- Lazarus R.S. & Folkman S. (1984). *Stress Appraisal and Coping*. New York: Springer.
- Law 2817 (2000). *Education of People with Special Educational Needs*. Athens: Greek Ministry of Education.
- Lingard, L, Albert, M & Levinson, W. (2008). Grounded theory, mixed methods, and action research. *British Medical Journal*, 337, 459-461.
- Luckasson R., Borthwick-Duffy S., Buntinx W., Coulter D.L., Craig E.M., Reeve, A. et al. (2002). *Mental Retardation: Definition, Classification and Systems of Supports*. Washington, DC: American Association on Mental Retardation.
- Michos, M. C., Mamolos, A.P. Menexes, G. Tsatsarelis, C.A, Tsirakoglou, V.M. & Kalburtji, K.L. (2012). Energy inputs, outputs and greenhouse gas emissions in organic, integrated and conventional peach orchards. *Ecological Indicators*, 13, 22-28.
- McConachie, H. (1994). Implications of a model of stress and coping for services to families of young disabled children. *Child: Care, Health and Development*, 20, 37-46.
- Mehta, C. & Patel, R. (1996). *SPSS Exact Tests 7.0 for Windows*. Chicago: SPSS Inc.
- Menexes, G. & Angelopoulos, St. (2008). Proposals for the financing and development of Greek farms based on a clustering method for categorical data. *EuroMed Journal of Business*, 3, 263-285.
- Michailidis, G. & de Leeuw, J. (1998). The gifi system of descriptive multivariate analysis. *Statistical Science*, 13, 307-336.
- Minnes, P.M. (1988). Family resources and stress associated with having a mentally retarded child. *American Journal on Mental Retardation*, 93, 184-192.

- Mojena, R. & Wishart, D. (1980). Stopping rules for Ward's clustering method. In: *COMPSTAT 1980 Proceedings*, Physica-Verlag, pp. 426-432.
- Neece, C.L., Green, S.A. & Baker, B.L. (2012). Parenting stress and child behavior problems: a transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities*, 117, 48-66.
- Olsson, M.B. & Hwang, C.P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 535-543.
- Padeliadou, S. (1998). Time demands and experienced stress in Greek mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, 42, 144-153.
- Peterson, G.W. & Mathieson, K. (2000). Understanding parental stress: a family perspective. In: P.C. McKenry & S.J. Price (Eds), *Families & Change: Coping with Stressful Events and Transitions* (pp. 71-93). Sage Publications, Thousand Oaks, CA.
- Quine, L. & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: a test of Lazarus' transactional model of coping. *Journal of Community and Applied Social Psychology*, 1, 57-70.
- Saiti, A. & Mitrosili, E. (2005). Parental perception of the education of their adolescent children: evidence from Greek secondary education. *Journal of Career and Technical Education*, 22, 19-30.
- Saloviita, T., Itäläinen, M. & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model. *Journal of Intellectual Disability Research*, 47, 300-312.
- Sanders J.L. & Morgan S.B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome. Implications for intervention. *Child and Family Behavior Therapy*, 19, 15-32.
- Schalock, R., Luckasson, R.A., Shogren, K.A., Borthwick-Duffy, S., Bradley, V., Buntinx, W. H. et al. (2007). The renaming of mental retardation: understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, 45, 116-124.
- Scott, B., Atkinson, L., Minton, H. & Bowman, T. (1997). Psychological distress of parents of infants with Down syndrome. *American Journal on Mental Retardation*, 102, 162-171.
- Sharma, S. (1996). *Applied Multivariate Techniques*. New York: John Wiley & Sons.
- Spaans, A. & Van der Kloot, W. (2004). *Permucluster 1.0 User's Guide*. Leiden: Leiden University.
- Taxidis, E.T., Menexes, G., Mamolos, A.P., Tsatsarelis, C.A., Anagnostopoulos, C.D. & Kalburtji, K.L. (2015). Comparing organic and conventional olive groves relative to energy use and greenhouse gas emissions associated with the cultivation of two varieties. *Applied Energy*, 149, 117-124.
- Tunali, B. & Power, T.G. (1993). Creating satisfaction: a psychological perspective on stress and coping in families of handicapped children. *Journal of Child Psychology and Psychiatry*, 34, 945-957.
- Turner, D. W. (2010). Qualitative interview design: a practical guide for novice investigators. *The Qualitative Report*, 15, 754-760.
- Tzouriadou M, Kontopoulou-Kokkinaki M. & Psinos, M. (2008). An inclusive early-intervention programme: the cases of a native-born and an immigrant preschooler. Paper Presented at *Early Childhood Intervention in Europe Conference*, 3-4 September 2008, Kristiansand, Norway.
- US Department of Education, (1995). *Seventeenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*
- Vlachos, F., Stavroussi, P. & Pisina, A. (2012). Handicappedness distribution in children and adolescents with genetic syndromes associated with intellectual disability. Paper presented at the *Sixth International Conference on Special Education and Rehabilitation*. Belgrade, Serbia.
- Van Riper, M., Ryff, C. & Pridham, K. (1992). Parental and family well-being in families of children with Down syndrome: a cooperative study. *Research in Nursing and Health*, 15, 227-235.
- Walker, L.S., Van Slyke, D.A. & Newbrough, J.R. (1992). Family resources and stress: a comparison of families of children with cystic fibrosis, diabetes, and mental retardation. *Journal of Pediatric Psychology*, 17, 327-343.
- Walton, W.T. (1993). Parents of disabled children burn-out too: counseling parents of disabled children on stress management. *International Journal for the Advancement of Counseling*, 16, 107-118.
- Westling, D. L. (1997). What parents of young children with mental disabilities want: the views of one community. *Focus on Autism and Other Developmental Disabilities*, 12, 67-78.
- Whemeyer, M. L. & Obremski, S. (2010). *Intellectual*

- disabilities. Available at: <http://cirrie.buffalo.edu/encyclopedia/en/article/15/> (accessed 22 September 2013).
- Wong, S.Y., Wong, T.K.S., Martison, I., Lai, A.C., Chen, W.J., & He, Y.S. (2004). Needs of Chinese parents of children with developmental disability. *Journal of Learning Disabilities*, 8, 141-158.
- Wulffaert, J., Van Berckelaer-Onnes, I., Kroonenberg, P., Scholte, E., Bhuiyan, Z. & Hennekam, R. (2009). Simultaneous analysis of the behavioural phenotype, physical factors, and parenting stress in people with Cornelia de Lange syndrome. *Journal of Intellectual Disability Research*, 53, 604-619.
- Ysseldyke, J.E. (1987). Classification of handicapped students. *Handbook of Special Education: Research and Practice*, 1, 253-271.

Νοητική ανεπάρκεια και στρες των μητέρων: Το παράδειγμα της Ελλάδας

ΚΩΝΣΤΑΝΤΙΝΟΣ ΒΟΥΓΙΟΥΚΑΣ¹, ΜΑΡΙΑ ΤΖΟΥΡΙΑΔΟΥ², ΓΕΩΡΓΙΟΣ ΜΕΝΕΞΕΣ³

ΜΑΡΙΑ ΓΚΕΚΑ⁴ & ΛΗΤΩ-ΕΛΕΝΗ ΜΙΧΑΛΟΠΟΥΛΟΥ⁵

ΠΕΡΙΛΗΨΗ

Έρευνες έχουν δείξει ότι οι γονείς παιδιών με νοητική ανεπάρκεια διακρίνονται από υψηλότερα επίπεδα άγχους σε σχέση με γονείς παιδιών τυπικής ανάπτυξης. Τρεις κύριες περιοχές πηγής γονεϊκού άγχους περιλαμβάνουν τη συννοσηρότητα της κατάστασης του παιδιού, τα γονεϊκά χαρακτηριστικά και τις καταστάσεις ζωής των γονέων. Ο σκοπός της παρούσας μελέτης ήταν η διερεύνηση των αντιλήψεων ελληνίδων μητέρων για τα χαρακτηριστικά των παιδιών τους με νοητική ανεπάρκεια και των συνθηκών της ζωής τους ως στρεσογόνους παράγοντες. Η έρευνα διεξήχθη στη Ρόδο. Στην έρευνα συμμετείχαν πενήντα εννέα μητέρες με παιδιά που είχαν διαγνωσθεί με μέτρια νοητική ανεπάρκεια με και χωρίς συννοσηρότητα. Για τη συλλογή των δεδομένων χρησιμοποιήθηκαν συνεντεύξεις. Κύρια ευρήματα της έρευνας ήταν ότι το στρες ποικίλλει μεταξύ των μητέρων των παιδιών με νοητική ανεπάρκεια και ότι η συννοσηρότητα των παιδιών με νοητική ανεπάρκεια φαίνεται να είναι ο πιο σημαντικός στρεσογόνος παράγοντας για τις μητέρες. Η υποστήριξη της οικογένειας θα πρέπει να βασίζεται στο μοντέλο εταιρικής σχέσης-ενδυνάμωσης. Περαιτέρω έρευνα σχετικά με τις ανάγκες της οικογένειας των παιδιών με νοητική ανεπάρκεια είναι απαραίτητη στην Ελλάδα, έτσι ώστε τα παιδιά να έχουν υποστήριξη σε όλη τη διάρκεια της ζωής τους.

Λέξεις-κλειδιά: Μέτρια νοητική ανεπάρκεια, Στρες μητέρων, Συννοσηρότητα, Οικογενειακή ενδυνάμωση.

1. Διεύθυνση: Τμήμα Επιστημών Προσχολικής Αγωγής και Εκπαίδευσης, Τομέας Ψυχολογίας και Ειδικών Αναγκών, Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης. Email: costasv@nured.auth.gr, τηλ.: +30 2310 991299
2. Διεύθυνση: Τμήμα Επιστημών Προσχολικής Αγωγής και Εκπαίδευσης, Τομέας Ψυχολογίας και Ειδικών Αναγκών, Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης
3. Διεύθυνση: Τμήμα Γεωπονίας, Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης
4. Διεύθυνση: Τμήμα Επιστημών Προσχολικής Αγωγής και Εκπαίδευσης, Τομέας Ψυχολογίας και Ειδικών Αναγκών, Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης
5. Διεύθυνση: Τμήμα Εκπαίδευσης. Το Πανεπιστήμιο της Πολιτείας της Pennsylvania