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A Comparative Study on Self Perceived Health and Quality of Life of Parents of Children with Autism Spectrum Disorders and Parents of Non Disabled Children in Croatia

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1. Introduction

Autism is defined as an organic developmental brain disorder that is manifested in difficulties in social interactions and communication, as well as unusual behaviors (Volkmar & Pauls, 2003; Gillham et al., 2000). Epidemiological report by the *Centers for Disease Control* (CDC) in Atlanta, USA, about autism spectrum disorders states the rate at 6.6 per 1000 births (Centers for Disease Control and Prevention [CDC], 2000). One of the leading experts in autism epidemiology, E. Fombonne, performed a meta-analysis of 32 epidemiological studies of autism spectrum disorders conducted between 1966 and 1991. Data was collected on the prevalence of autism spectrum disorders in 13 different countries on a sample of nearly five million inhabitants. According to this research, of 10,000 live births, 13 people are born with autism and 3 people are born with Asperger's syndrome. Another study found that 60 people of 10,000 live births have autism spectrum disorders (Fombonne, 2005). The term autism spectrum disorders (ASD) was officially used in Croatia, according to the International classification of diseases, Tenth Revision (ICD-10) published by World Health Organization. Global report of health status in European Union for 2007, underlines the diverse criteria for the diagnostic of ASD and the methodology which produces different prevalence. For example in Cambridgeshire (United Kingdom) total rate, in the age group 5-11, was 57 per 10,000 while in Nord-Trøndelag (Norway) with same used criteria (DSM-IV) total rate, in the age group 3-14, was 3.8 per 10,000 (European Commission Health & Consumer Protection Directorate, 2005). Consequently, harmonization of the above segments is needed. In the Global report data for Croatia are not included, but they are available from the Croatian Disabilities Registry. Croatia regulates the collection of data on persons with ASD via the Croatian Disabilities Registry Act, according to which ASD are distinguished as a separate disability category. The prevalence of ASD in child population (0-18) in Croatia is approx. 1 in 1000, three times more common in boys (Croatian Public Health Institute, 2008).

While caregiving is a normal part of being the parent, providing the high level care required by a child with long-term functional limitations can become burdensome and may impact upon both the physical and mental health of the parents. A series of studies has been published about subjective health and health-related quality of life of family caregivers. Previous studies on family caregivers of people with chronic health problems revealed higher level of burden, stress, and depression (Canam & Acorn, 1999). Although it has been argued that all chronic illnesses and disabilities of children can negatively affect health-related quality of life of the parents; each disease present unique challenges (Epstein et al., 2005; Raina et al., 2005). According to some authors (Blanchard et al., 2006; Olsson & Hwang, 2001), parents of children with ASD are a particularly vulnerable group as they take over practically the entire burden of family care for their severely disabled child. Parenting children who have ASD was related to the impaired wellbeing of the parents themselves (Allik et al., 2006), their higher morbidity of anxiety, depression (Olsson & Hwang, 2001; Bailey et al., 2007) and obsessive compulsive symptoms (Abramson et al., 2005). Caregivers also reported somewhat lower marital happiness, disturb family cohesion, and family adaptability (Higgins et al., 2005). Moreover, an analysis of both qualitative and quantitative data indicate that primary carers report substantially low subjective quality of life (SQoL) (Cummins, 2001).

In the process of deinstitutionalization persons with intellectual disorders, parents of children with ASD become, also a key factor for improving the functioning of their children (Early et al., 2002). According to the latest guidelines on therapy and rehabilitation of children with ASD (daily lifetime therapy), and from the standpoint of harmony in all life aspects of the child, parents assume to have a very important role in the care and rearing (Olsson & Hwang, 2008; Welch, 1997). For parents to be able to care for their child with ASD and contribute to the quality of their child's rehabilitation procedure, they need, more than anything else, to be of good health themselves, as this care will exert great psychological and physical efforts (Kelly & Hewson, 2000). Because the parents are in the centre of support for the needs of the child with intellectual disability and ASD (Turnbull et al., 2004), preserving parents' good health and well being is precondition for optimal care for child. Poor caregiver health may contribute to recurrent hospitalizations (Kelly & Hewson, 2000) and out-of-home placements for children with chronic conditions and disabilities (Bromley & Blacher, 1991; Llewellyn et al., 1999; Duvdevany & Vudinsky, 2005). The therapy and rehabilitation of persons with ASD in Croatia is mostly administered in the Zagreb Autism Center, which conducted this study. The Center has its branch offices in Split, Rijeka and Nova Gradiška. The same institution administers rehabilitation and therapeutic measures for 333 persons. The inpatient unit accommodates 89 patients, 37 of whom never come into contact with their parents. This mode of care, which includes persons who have ASD into day therapeutic rehabilitation programs while being placed in the care of the family, is in line with the global trends of care and social inclusion of persons with ASD (Hare et al., 2004; Hastings & Johnson, 2001). According to these facts and data that over 80% of persons with ASD in Croatia live with their families (Croatian Public Health Institute, 2008) we think that is necessary to assess health and quality of life of parents who are at the same time caregiver for their disabled children. The purpose of this study was to examine self-assessed health, quality of life and chronic medical conditions in parents of children with ASD, and compare with parents of non-disabled children in Croatia. The starting hypothesis was that parents of children with ASD, due to required child care, have a lower self-assessed health

with lower quality of life and higher chronic medical conditions’ load, which may contribute to more frequent chronic diseases in comparison with parents of non-disabled children. This is one of the aspects of community efforts to provide social support which are one of the important factors for these families (Whitaker, 2002; Brown et al., 2003).

2. Participants and methods

2.1 Participants

The study included 178 parents of children with ASD (diagnosed under code F84 of ICD-10) median age 43 yrs (27-83yrs), of which 105 were mothers (59%) and 73 were fathers (41%). The control group was 172 parents of non-disabled children, median age 42 yrs (24-82 yrs), of which 101 were mothers (58.7%) and 71 were fathers (41.3%). A majority of respondents in both groups were married, though a higher number of single parent families existed in the group of parents of children with autism spectrum disorders (11.2%), as compared with 9.3% of parents of non-disabled children. About third of respondents had a university education (37.1%), with a distribution over all educational fields (Table 1).

Characteristic	No. (%) of parents of		P
	child with autism spectrum disorders (ASD) (n=178)	non-disabled child (n=172)	
Mother / Father	105 (59) / 73 (41)	101 (58.7) / 71 (41.3)	0.886 *
Family status:			
both parents	158 (88.7)	156 (90.7)	0.675 *
single parent	20 (11.2)	16 (9.3)	
Education level:			
primary	17 (9.6)	13 (7.6)	0.729 *
secondary	96 (53.9)	91 (52.9)	
university	65 (36.5)	68 (39.5)	
Median age (min-max. years)	43 (27-83)	42 (24-82)	0.822**

* χ^2
** Man Whitney U-test

Table 1. Demographic data of the study participants

There was no difference between groups in respect to family status, education level, and age. The sample included 83.7% parents of male children with autism spectrum disorders and 16.3% parents of female children with autism spectrum disorders. Parents of children with ASD were contacted through the Croatian Autism Center in Zagreb and its branch offices in Rijeka, Split and Nova Gradiška, and educational centers for children with disability in Pula and Osijek. The Centres database of users was basis for sample frame. Targeted sample were the parents whose children were at the time clients of the above centers. The research was conducted in 29 Croatian municipalities. Parents were approached at the Parents meetings at the Centres and individually when they came to Center (if they didn’t attend the meetings). The purpose of the study was presented to parents by project

leader at the Parents' meetings. Questionnaires were distributed personally by Centers staff and project leader to parents (both mothers and fathers) who agree to participate in the study. All together 250 questionnaires distributed to parents. Each questionnaire has a cover letter with information about research. 178 of them responded with correctly filled questionnaire within the given deadline. The original plan was to have both of the parents fill out the questionnaire. However some 20% less fathers responded. The matching control group of parents was based on the following characteristics of the collected group of parents with children with ASD: sex and age of children (+/- 5 yrs), parent age group (+/- 5 yrs), and educational background of parents and municipality of residence. Data collection for the control group was organized as part of the primary health care and primary schools in municipalities of residence of parents with children with ASD. Participants for the matching control group were searched one by one according to list of participants in already collected first group. Family doctors and school administration were provided with the list of first group participants and their key characteristics according to which they selected matching parent from their client database.

This research was conducted under the Croatian National Strategy of Equalization of Possibilities for Persons with disabilities with the written approval of the Ministry of Family Affairs, War Veterans and Intergenerational Solidarity as a coordinator of the Strategy.

2.1.1 Measures

Parents' self-perceived health was assessed using the health status questionnaire SF-36 - Croatian version (Ware et al., 1993; Maslić Seršić & Vuletić, 2006). SF-36 is a multi-purpose, short-form health survey that consists of 36 questions (Ware et al., 1993). It represents a theoretically based and empirically verified operationalization of two general health concepts, physical and psychological, and their two general manifestations, functioning and well-being. Accordingly, the questionnaire contains four types of scales, or four conceptually different measures of health. They refer to the following assessments or indicators of health: a) functioning at the behavioral level, b) perceived well-being, c) limitations connected with social life and the realization of central life roles, and d) direct personal perception of total health. At the manifested level, each of the questionnaire items refers to one of the following eight different health indicators (24): physical functioning (10 items); role-physical, referring to the limitations in performing important life roles due to physical health (4 items); bodily pain (2 items); general health (5 items); vitality and energy (4 items); social functioning (2 items); role-emotional, referring to the limitations in performing important life roles due to emotional problems (3 items); mental health, referring to the absence of anxiety and depression (5 items); and one final self-evaluated health transition item (five levels from "much better than a year ago" to "much worse than a year ago"), which is not used in the score of any of the scales but is useful in estimating average change in health status over a year before its administration. Five questionnaire scales - physical functioning, role-physical, bodily pain, social functioning, and role-emotional - define health as the absence of limitations and inability, so they represent continual and one-dimensional health measures. The three remaining scales - general health, vitality, and mental health - are bipolar, meaning they measure a much wider range of negative and positive aspects of health. The physical functioning, role-physical, and bodily pain scales refer to the general factor of physical health, and social functioning, role-emotional, and mental health scales measure psychological health. Scales vitality and general health are moderately connected with both factors. The total result is shown in the

form of the profile defined with eight points that represent the measure of individual aspects of health transformed into a standardized score from 0 (minimum) to 100 (maximum). On all scales, higher results indicate better subjective health. Psychometric validation revealed good psychometric properties of the Croatian version of the SF-36 (Maslić Seršić & Vuletić, 2006). The Croatian version of SF-36 questionnaire was licensed to Andrija Štampar School of Public Health and using permission was obtained.

In this research, a multidimensional approach was used to measure QoL (Cummins, 1996). Parents' subjective QoL was assessed using the Personal Wellbeing Index (PWI; International Wellbeing Group, 2006). The PWI scale contains seven items of satisfaction, each one corresponding to a quality of a life domain: standard of living, health, achievements in life, close relationships, personal safety, community connectedness, and future security. These seven domains theoretically represent the first level deconstruction of the global question: "How satisfied are you with your life as a whole?" The overall Personal Wellbeing Index score is an aggregate average score across the seven domains. Each domain is rated on a bipolar 11-point (0-10) end-defined scale where 0 means 'completely dissatisfied' and 10 is 'completely satisfied'. PWI has satisfactory metric characteristics; Cronbach alpha lies between .70 and .85. Inter-domain correlations are often moderate at around .30 to .55 and item-total correlations are at least .50. The index has also demonstrated good test-retest reliability across 1-2 week intervals with an intra-class correlation coefficient of 0.84 (International Wellbeing Group, 2006). Furthermore, parents filled out a general questionnaire containing three parts: demographic part (sex, age, marital status, parent educational background, as well as child's sex and age); health part including questions on self-reported chronic medical conditions, and the part on the needs and defining the type of help considered important by parents to advance their health and well-being.

2.1.2 Statistics

Descriptive statistics was used to present data on sex, age, family status and education level of study participants. Original results from health status questionnaire SF-36 and PWI were transformed according to authors' algorithm which results in 8 health dimensions and 7 domain of quality of life. The results from PWI domains and for the overall QoL index were transformed and presented in a standard form of the "percentage of scale maximum" (%SM), means original results were transformed to a 0-100 point scale. This conversion does not alter the statistical properties of the data, since the process is a simple linear conversion, with the advantage that the data from the PWI and other scales is compared directly in terms of mean and standard deviations. The differences self-perceived health between the two groups were assessed with Mann-Whitney U test since distributions were not normal. Difference in distributions of categorical data was tested with chi-square test. To assess the impact of the variables measured for the QoL in parents of children with autism spectrum disorders, bivariate and multiple logistic regression analysis were used. The dependent binary variable - quality of life - was defined as high ($PWI \geq 60\%SM$) or low ($PWI < 60\%SM$). In determining the above values, data from the Croatian National Survey was used which was conducted on 9070 adult participants and revealed an average satisfaction with quality of life at 60% SM (Vuletić, 2006). Numerical variables were tested for linearity in logit, while all variables were tested for co-linearity. The level of statistical significance was chosen as $\alpha = 0.05$.

Statistical analysis was performed by statistical software Statistica, ver.7,1 (STATISTICA, 2005).

2.2 Results

2.2.1 Self perceived health and chronic medical condition

For all dimensions of health, except for physical health, there was a significant difference in self-assessed health between parents of children with ASD and parents of non- disabled children (Table 2).

Score median (interquartile range) for the parents of			
Health dimension	child with autism spectrum disorders (ASD)	non-disabled child	P*
Physical functioning	80.0 (40.0)	80.0 (30.0)	0.118
Role physical	75.0 (78.5)	100.0 (25.0)	0.000
Role emotional	66.7 (100)	100.0 (33.3)	0.000
Social functioning	55.6 (22.3)	77.8 (22.2)	0.000
Mental health	52.0 (22.0)	72.0 (20.0)	0.000
Vitality/Energy	50.0 (30.0)	60.0 (15.0)	0.000
Bodily pain	60.0 (40.0)	70.0 (30.0)	0.000
General health	57.0 (27.0)	67.0 (20.0)	0.000

* Man Whitney U-test

Table 2. Eight health status dimensions and significance of difference between two groups of study participants

The worst dimensions of health in parents of children with ASD are the energy, vitality and social functioning dimension. Thirty-five percent of parents of children with ASD reported their health deteriorated in the last year which is 18% higher than in parents of non-disabled children (Table 3). The difference between the groups were statistically significant ($\chi^2 = 17.500$, $df = 4$, $P = 0.002$).

No. (%) of parents of		
Change in health during the last year	child with autism spectrum disorders (ASD)	non-disabled child
much worse	10 (5.6)	2 (1.2)
somewhat worse	52 (29.4)	27 (15.7)
about the same	96 (54.2)	115 (66.8)
somewhat better	11 (6.2)	20 (11.6)
much better	8 (4.5)	8 (4.7)

Table 3. Frequency distribution for the item 'change in health during the last year' for two groups of study participants

Furthermore, 41% of parents of children with ASD stated that they suffered from a chronic medical condition, as well as 30.2% of parents of non-disabled children. Due to data distributions with small frequencies in several categories test statistics was not performed.

However, we could observe that most common chronic medical conditions listed by parents of children with ASD were those of the musculoskeletal system and connective tissue (21,2%), and circulatory system (17,3%), while parents of non-disabled children stated medical conditions of respiratory system (27,1%). Furthermore, it was noticeable in Table 4, that 11% parents of children with ASD suffered from psychological disorders (F00-F99 ICD-10 code group) what was 6,7% above frequency for parents of non-disabled children what was the largest difference in specified chronic medical conditions between the examination groups.

Group of disease according to ICD-10 (code)	No. (%) of parents of	
	child with autism spectrum disorders (ASD)	non-disabled child
Communicable and parasitic diseases (A00-B99)	2 (1.6)	1 (1.4)
Neoplasm's (C00-D48)	6 (4.7)	2 (2.9)
Endocrine, nutritional and metabolite diseases (E00-E90)	19 (15)	9 (12.8)
Mental and behavioral disorders (F00-F99)	14 (11)	3 (4.3)
Diseases of the nervous system (G00-G99)	8 (6.3)	3 (4.3)
Diseases of the eye and ear (H00-H95)	3 (2.4)	2 (2.9)
Diseases of the circulatory system (I00-I99)	22 (17.3)	10 (14.3)
Diseases of the respiratory system (J00-J99)	8 (6.3)	19 (27.1)
Diseases of the digestive system (K00-K93)	14 (11)	5 (7.1)
Diseases of the skin and subcutaneous tissue (L00-L99)	1 (0.8)	3 (4.3)
Diseases of the musculoskeletal system and connective tissue (M00-M99)	27 (21.2)	11 (15.7)
Diseases of the genitourinary system (N00-N99)	3 (2.4)	2 (2.9)
Total	127 (100)	70 (100)

Table 4. Chronic medical conditions reported by two groups of study participants according to International Classification of Diseases Tenth Revision (ICD-10) disease group

2.2.2 Quality of life

Descriptive statistics and difference statistics for PWI scores on seven QoL domains and overall index for the two sample groups are shown in Table 5. The results show that parents of children with ASD have statistically significantly lower subjective QoL ($p < 0.001$) as compared to parents of non-disabled children in all domains of QoL, as well as in overall PWI scores. Both groups were least satisfied with their future security, with a significantly low score in the group of parents of children with ASD, indicating strong dissatisfaction. In the domain of 'future security' a major difference is noticeable in the dominant answer, where parents of children with ASD were predominantly completely dissatisfied (mode = 0) and the control group of parents of non-disabled children was mostly highly satisfied (mode = 80). Parents in both groups were most satisfied with the 'close relationships' domain. Although parents of children with ASD were significantly less satisfied than parents of non-disabled children, this was the domain that contributed to lowering their total QoL.

	Parents - child with autism spectrum disorders			Parents - non-disabled child			
Domain	N	M	SD	N	M	SD	t-test
Standard of Living	177	48.6	26.5	169	63.7	21.9	-5,759**
Personal Health	177	58.5	26.9	169	70.7	20.7	-4,730**
Achievements	176	53.9	26.2	169	71.1	19.1	-6,965**
Close relationships	177	66.0	28.2	169	79.6	20.1	-5,189**
Personal safety	177	43.7	31.8	169	67.0	23.5	-7,785**
Community	177	49.3	30.7	169	70.9	24.5	-7,233**
Future security	177	35.3	28.3	169	55.3	25.5	-6,925**
PWI	176	50.67	23.02	169	68.33	16.93	-8,140**

** p<0.01

Table 5. Means and standard deviations (%SM) for seven domains and overall personal wellbeing (PWI) scores and test statistics for the two groups of parents

Bivariate logistic models found 10 variables to be significant (age of parent, age of disabled child, presence of chronic disease and all seven domains of PWI) and 4 insignificant (parent and child gender, level of education and marital status). Nevertheless, in the multiple logistic model, only 5 variables remained statistically significant (age of parent and disabled child, and these PWI domains: achievement in life, personal relationships and future security). The results of the multiple logistic regression analysis are shown in Table 6.

Variable	Odds ratio (OR)	Standard error for OR	p value	95% confidence interval for OR	
Parent age	0.693	0.094	0.007	0.531	0.905
Age of child	1.277	0.152	0.040	1.010	1.612
Achievement in life	3.762	1.508	0.001	1.716	8.253
Personal relationships	4.890	2.063	0.001	2.138	11.181
Future security	13.316	10.556	0.001	2.815	62.975

Table 6. Multiple logistic model for outcome achieving high quality of life (PWI≥60%SM)

2.3 Policy measures

When asked whether they felt that certain measures could improve their health and well-being 71% of parents of children with ASD thought that enhancing different policy measures which applied to them and their children with ASD (economic, social, educational, etc.) could advance their health and well-being. They defined over 60 different measures which could be undertaken or advanced to improve their quality of life. Three most commonly suggested measures were: financial aid to parents; a comprehensive system of diagnostics, therapy and rehabilitation to enable a better integration of individual in the community; and the need for more institutions and for advancing the quality of the existing ones (table 7).

Measures	N(%)
Financial assistance for parents	35 (20)
The complete system diagnostics, therapy and rehabilitation of ASD that will provide an opportunity to better integrate person into society	31 (17)
The need for more facilities and improving the quality of existing	26(15)
Improvement of health policy and health care for parents and children	20 (11)
Improvement of social policy	16 (9)
Sensitization of society	13 (7)
Creating the conditions for housing	11 (6)
Education for parents	11(6)
Psychological help for parents	10(6)
Provide non-institutional forms of care (playgroups, organized trips, etc.)	9 (5)

Table 7. Ten most common measures, which in the opinion of parents of child with autism spectrum disorders, could be undertaken or advanced to improve their quality of life

2.4 Discussion

Study results confirm the hypothesis regarding the difference in self-perceived health between parents of children with ASD and parents of non-disabled children in a sense of significantly poorer health for all dimensions, except for physical health, of parents of children with ASD. Energy and vitality and social functioning were particularly deteriorated dimensions. The only dimension of health in which there was no difference in relation to the parents of non-disabled children was physical health, which can be explained by the fact that 71% of surveyed parents with children with ASD were under 50 years of age. Especially important is the fact that even 35% of parents of children with ASD perceived their health as worse than last year, which was 18% higher in comparison to parents of non-disabled children. This discrepancy in self-perceived health between parents was confirmed by the finding that 41% of parents of children with ASD, in comparison with 30% of parents of non-disabled children, reported the existence of a chronic medical condition, with about three times higher frequency of psychological disturbances than the parents of non-disabled children, what was the largest difference in specified chronic medical conditions between the examination groups (Table 4). The research results also confirm the hypothesis regarding the difference in the SQoL between parents of children with ASD and parents of non-disabled children. The first group had lower SQoL. It was also confirmed that, despite the difficult situation of parents of children with ASD, there are parents who have SQoL levels in the normative range for the general population. Overall SQoL scores for parents of non-disabled children were within the range of expected values for the non-disabled adult population, while 62% of parents of children with ASD scored below 60%SM, with the average overall SQoL measured at 50.8%SM. This finding is of particular concern, as the latter value, according to references, is below the global normative range of the general population, which is 60-80%SM (Cummins 2000; Cummins et al. 2003), and the Croatian average of 60.1 %SM from a national health survey conducted in 2003 (Vuletic 2006). The fact that persons who suffer from a challenged homeostasis when their QoL falls below 60%SM develop symptoms of depression points to the significant vulnerability of this population (Cummins and Nistico 2002). Despite all of the above facts we identified parents

of children with ASD who have the same level of QoL as the general population in Croatia (Vuletic 2006). Thirtyeight percent of parents of children with ASD, retain SQoL equal to, or even better than, the general Croatian population, which indicates that they may have developed resilience to the existing situation. Regression analysis shows that the ages of the parents and the disabled child, satisfaction with achievements in life, close relationships and future security are statistically significant in predicting a higher SQoL for the group of parents of children with ASD. These may, consequently, be deemed to be protective factors in maintaining a normal SQoL. The existence of parents who have a normal quality of life draws attention to community supports and services. All these facts are consistent with research conducted in the world (Blanchard et al., 2006; Olsson& Hwang, 2001; Allik et al., 2006; Bailey et al., 2007) which indicate that the parents of children with ASD are a particularly vulnerable and that the parenting disabled children who have ASD was related to the impaired their wellbeing. In order for the care of disabled family member to have a positive effect on the family according to world authors (Olsson& Hwang, 2008; Yau& Li-Tsang, 1999; Cummins, 2001) parameters are needed which enable the above hypothesis. These parameters are: harmonious family relationships, high socio-economic status and the community which supports such families. Unfortunately in Croatia all of the above is in disharmony with the parameters that should exist for the care for a disabled family member to have utterly positive impact on the family. The findings that in Croatia the percentage of divorce in families with children with ASD is higher by about 2% than in families with healthy children, that Croatia is a post-war country with a low GDP and one of the poorest countries in Europe (Eurostat, 2009), and that the poorest dimensions of health in parents of children with ASD are energy, vitality and social functioning dimensions, indicate possible deviations from the parameters that, according to Yau and Li-Tsang (Yau& Li-Tsang, 1999), guarantee the highest quality of parenthood to a disabled child, including children with ASD. All those findings, and especially the fact that the health of parents with children with ASD compromised, are the potential threat to optimal care for child (Kelly& Hewson, 2000; Bromley& Blacher, 1991; Llewellyn et al., 1999; Duvdevany& Vudinsky, 2005). All discussed facts have resulted in the finding that a great majority (71%) of parents of children with ASD believes that enhancing different political aspects would contribute to or improve their situation, quality of life and health, focusing of the social, economic and health policy, as well as streamlining the legislature, when it comes to parents of children with ASD. Parents from our study gave a series of proposals which may be summarized as measures for enhancing their, and by extension their children's, health and quality of life. These measures would include sensitization and education of the society on the issue of ASD, advancing the educational system and integration of children with ASD in the society, categorizing autism as 100% disability and claiming the pertaining rights, advancing the organizational aspects focusing on better service staffing and accommodation for children with ASD, introducing personal assistants, as well as a legal provision for mothers with the career status. All the above listed may directly or indirectly have a bearing on improving health for the group of parents of children with ASD.

However, there are some factors that limit the generalizability of our results and they are associated with the methodology used in our study. Sample of parents was not random from open population; in survey participated only parents with children in Autism Center, from them only those who voluntarily answered the questionnaire. In that way group of parents of children with ASD was pre-selected comprise those who already receiving

various support through Centres. We are aware that sample omits those parents who were, for example, dislocated and from whatever reason unable to use Centers. According to Croatian register (Croatian Public Health Institute, 2008) there are about 800 persons with diagnosed ASD living in Croatia, and Centers uses about 1/3 of them. So we may expect to find even more difficulties and health problems in the population of all parents of children with ASD. However, we try to overcome this limitation with the matching control group.

3. Conclusion

Parents of children with ASD had poorer health and quality of life than the control group in all components, except physical health. Because the parents are in the focus of support for the needs of the child with ASD, preserving parents' good health and well being is precondition for optimal care for child, so current system for treating children with ASD in Croatia should also include permanent improvements their health and well-being. With our findings and with the type of help what parents of children with ASD specified that is important to advance their health and well-being we want provide the basis for permanent improvements their health and well-being. In the world special attention is devoted to the improving caregiver well-being (Brown et al., 2003; Mittelman et al., 2006; Hebert et al., 2007). Organized support for family caregivers benefits the patient, but also the caregiver, and the healthcare team (Glajchen, 2004; Herring et al., 2006). Croatia has regulations on disabled persons, but these do not define or give enough significance to the disability in ASD persons and persons with other intellectual disorders. It should be pointed out that ASD, like other intellectual disorders, are not covered by a single legal provision to determine the degree of disability. Completing legal provisions, familiarizing parents with their rights, as well as interdepartmental cooperation, combined with empathy for disabled persons, will result in improving the position of persons with ASD and their families. In addition to streamlining the legislation, it is necessary to stress the importance of early diagnostic of pervasive developmental disorders, application of a suitable life-long approach, as well as giving support to the family and experts included in the treatment (Landa, 2008; Chawarska et al., 2007). Our results suggest that the current system for treating children with ASD in Croatia should also include close monitoring of parents' health and well-being. Appropriate treatment and psycho-social support should be provided before the health of parents becomes seriously compromised. Such measures, besides encouraging a positive attitude in the society, may improve the well being of autistic persons and their families. Additional attention should be focused on especially vulnerable groups of parents of children with ASD that we identified which needs for support and help are greater than needs of other. The National Strategy of Equalization of Possibilities for Persons with disabilities for 2007-2015 stresses the importance of interdepartmental collaboration for the improvement of well being of all disabled persons and their families, as well as persons with ASD. The strategy also points out that Croatia is among the first signatories of the Convention on the Rights of Persons with Disabilities. It is these two acts that serve as guidelines on how to improve the position of disabled persons in Croatia.

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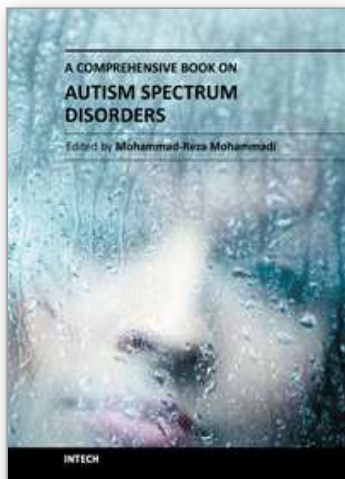
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