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Prevalence of Pervasive Developmental Disorders – Croatia in Comparison with Other Countries of the World

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1. Introduction

Disabled persons live in every corner of the world and on all social levels. According to UN estimations, disabilities are much more widespread than is believed: at least one in every 10 inhabitants of each country has a certain form of disability, totaling some 450 million people around the world. [1] According to the 2001 census, Croatia had at that time 423 891 persons with disabilities (10% of overall population) [2]. According to the Croatian Disabilities Registry (the Registry), [3], Croatia has 518 081 disabled persons (ca. 12% of overall population). As defined in the Act on the Croatian Disabilities Registry, disability is a limitation or reduction (resulting from damaged health) the capacity to perform a certain physical activity or psychological function normal for a person of a certain age, and refers to the abilities which are manifested in complex activities and behaviors generally accepted as important components of everyday life [4]. Croatia has defined the collection of data on disabled persons in the Act on the Croatian Disabilities Registry (Official Gazette No. 64/01). The Registry includes data on the following types of physical and mental impairments: visual, hearing and speech impairments, impairments of the locomotor, central and peripheral nervous systems, other organs and organ systems, mental retardation, PDDs (autism), mental disorders, as well as data on multiple impairments. PDDs (autism) have been separated as a special disability category. The data on the above disorders is provided by expert evaluation bodies within the education and social welfare system [4]. According to the references, PDD prevalence has registered a continual rise. To illustrate, according to the CDC Report from Atlanta, USA, prevalence numbers 6.6 per 1000. [5, 6, 7, 8, 9]. The data on individuals with PDDs in Croatia is registered in the above Registry. However, due to a short history (since 2002), the extent of the potential increase could not be determined.

2. Epidemiology of PDDs globally

2.1. Classification systems

For the purpose of learning more about the epidemiology of autism, and, by extension, about the changes in its prevalence, the following part will present two classification systems that have been in international use for many years, together with clearly stated criteria and diagnostic instructions that need to be abided by so as to correctly diagnose autism and PDDs. The two systems are: WHO's ICD-10 (*International Statistical Classification of Diseases and Related Health Problems*) and DSM (*Diagnostic and Statistical Manual of Mental Disorders*) by the American Psychiatric Association (APA). ICD-10 defines autism under a three-sign category of F84: Pervasive developmental disorders. This group includes, codes and defines the following: childhood autism (F84.0), atypical autism (F84.1), Rett's syndrome (F84.2), other childhood disintegrative disorder (F84.3), overactive disorder associated with mental retardation and stereotyped movements (F84.4), Asperger's syndrome (F84.5), other pervasive developmental disorders (F84.8), as well as pervasive developmental disorder, unspecified (F84.9) [10]. PDD is also defined by the APA's DSM classification. DSM introduced the term of pervasive developmental disorder for the first time in its third revision from 1980. The term pervasive was selected so as to accentuate the fact that this psychopathological manifestation assumes all of child's spheres of functioning. In DSM Revision III from 1987 PDDs encompass a significantly wider spectrum of symptoms, which has led to an increased prevalence. The term infantile autism was changed to autistic disorder. All non-autistic pervasive disorders are specially categorized as pervasive developmental disorders not otherwise specified (PDDNOS). Out of a need to maximize the quality of diagnostics and create clearer diagnostic criteria DSM-III has grown into DSM-IV (DSM-IV-TR, APA, 2000). The latter classification calls for an introduction of a new term: autism spectrum disorders (ASDs), which now defines autism [11, 12]. ASDs ultimately include: autistic disorder (AD), Asperger's syndrome (AS) and PDDNOS. An approximation of the two above classification systems is visible in a series of elements. What is significant is that both currently acknowledge a separate category of pervasive developmental disorders, though the two selections of clinical entities encompassed by this category remain diverse. Table 1 outlays nosological categories belonging to PDDs in the ICD-10 and DSM-IV-TR. By analyzing Table 1 a similarity can be noticed between the above classification systems in determining clinical entities belonging to PDDs. Solely hyperkinetic disorder related to mental retardation and stereotyped movements is left out of the DSM-IV-TR [13]. The American Psychiatric Association (APA) has proposed new diagnostic criteria for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) for autism. While final decisions are still months away, the recommendations reflect the work of dozens of the nation's top scientific and research minds and are supported by more than a decade of intensive study and analysis. The proposal by the DSM-5 Neurodevelopmental Work Group recommends a new category called autism spectrum disorder which would incorporate several previously separate diagnoses, including autistic disorder, Asperger's disorder, childhood disintegrative

disorder and pervasive developmental disorder not otherwise specified [14]. Croatia applies ICD-10 codes for PDD diagnoses.

ICD-10 (WHO, 1992)		DSM-IV-TR (APA, 2000)	
F 84.0	Childhood autism	299.00	Autistic disorder
F84.1	Atypical autism		PDDNOS
F 84.2	Rett's syndrome	299.80	Rett's disorder
F84.3	Other childhood disintegrative disorders	299.10	Childhood disintegrative disorder
F 84.4	Overactive disorder associated with mental retardation and stereotyped movements		
F84.5	Asperger's syndrome	299.80	Asperger's disorder
F84.8	Other pervasive developmental disorders		PDDNOS
F84.9	Pervasive developmental disorder, unspecified	299.80	PDDNOS

Table 1. Overview of PDD categories in ICD-10 and DSM-IV-TR.

2.2. Epidemiological studies on autism

The first epidemiological study of autistic disorder was published in 1966. Viktor Loter, the author, thereby informed the health public that the prevalence of autistic disorder was low, namely four to five autistic children per 10 000 inhabitants [15]. Epidemiological studies in 1980s and 1990s registered a significant increase in the prevalence of autistic disorder in different parts of the world. Research done in Wales has shown that autism prevalence in respondents born between 1977 and 1979 was 3.3, while the prevalence in the population born between 1987 and 1989 9.2 [16]. The prevalence of autism in Iceland grew from 4.2 persons in respondents born between 1974 and 1983 to 13.2 in the population born between 1984 and 1993 [17]. A stable growth in the prevalence of autism during the 1980s and 1990s was also registered in California [18]. Having analyzed a sample of some 300 000 respondents born between 1988 and 1996, Honda noted that the incidence of autism grew from an earlier 54 to the present 88 persons, with the highest oscillation being registered in the 1990s [19]. Fombonne conducted a meta-analysis of 32 epidemiological studies on autistic disorder carried out between 1966 and 2001. Data was collected on the prevalence of autistic disorder in 13 different countries on a sample of nearly 5 million people. According to the epidemiological research of the same author, 13 in 10 000 liveborn children are born with autism, 3 with Asperger's syndrome, and 60 with PDDs [20]. Similar data are found in studies of other authors (21,22). According to the CDC Report, the prevalence rate for autism numbers 6.6 per 1000 [5, 6, 7, 8]. Autism more commonly appears in boys, accounting for the ratio of 4.3:1 in favor of boys [13]. According the cohort study of children in South Thames prevalence of ASD was about 1% [23] while in the past year a new epidemiological study rates closer to 2% [24]. Regarding the prevalence of PDDs in EU countries, EUGLOREH 2007 stressed the diversity of the definition of autistic disorder and

methodology yielding and monitoring prevalence, which is confirmed by Table 2. Specially stressed is the need to approximate the above segments [25].

Area	Year	Total children in age range	Criteria used	Age range	Total rate per 10 000
Aarhus (Denmark)	1972	46 500	Kanner	2-14	4.3
Camberwell (UK)	1979	34 700	Kanner	3-17	4.9
Cambridgeshire (UK)	1999	34 262	DSM-IV	5-11	57
Västerbotten (Sweden)	1983	69 600	Rutter	0-20	5.6
Göteborg1 (Sweden)	1984	128 600	DSM III	4-18	4
Göteborg2 (Sweden)	1986	42 900	DSM III	0-10	7.5
Göteborg3 (Sweden)	1991	40 700	DSM III - R	4-13	11.5
Rhône (France)	1989	103 700	Rutter	5-9	10.8
Iceland	1996	38 746	Rutter	4-12	8.8
Nord-Trøndelag (Norway)	1998	n.a.	DSM-IV	3-14	3.8
Northern Finland	1997	152 732	DSM III – R/DSM-IV	5-7	20.7
Ireland East	1997	549 255	DSM III /DSM III - R	0-25	4.94

Table 2. Overview of the prevalence of autistic disorder in EU countries.

The above data leads to the conclusion that the prevalence of autistic disorder in the last 50 years has increased as much as 15 times. Does that mean that the modern world is facing a kind of an *autism epidemic*? Despite a series of studies conducted to establish a potential cause of the same increase, and, by extension, possible etiology of the disorder, [26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38], many authors continue to believe that the prevalence of autistic disorder in the 21st century remains as it was 50 years ago [13]. The same authors argue that this increment is due to more precise diagnostics, changes in diagnostic criteria and a greater sensitization of the public for the problems of autistic persons. This increase in the prevalence of autism in the past decades was mostly registered in persons of preserved intellectual capacity [39], which would argue that the prevalence in persons with typical autism has remained virtually unchanged.. At this moment it has still not been confirmed or denied that various factors (pollutants, diet, etc.) have a certain effect on the incidence and prevalence of autistic disorder but there is clear scientic evidence that no causal relationship between vaccination and autism [40]. Consequently, no definitive causes of the incurred increase in the prevalence of the above disorder can still be determined [13].

3. Prevalence of PDDs in Croatia

Croatia monitors data on persons with PDDs within the scope of the Registry. PDDs are therein separated as a special type of disability and monitored according to the ICD-10 un-

der the three-sign category of F84. The onset of a systematic epidemiological monitoring of data on PDDs goes back to the introduction of the Registry in 2002. The data on the above disorders is provided by expert evaluation bodies within the education and social welfare system. These expert evaluation bodies hire experts who are to thank for PDD diagnostics. The Registry database, as up until 4 May 2012, contains data on 1109 persons with PDDs, with the largest number of registered under the diagnosis F84.9 (Table 3).

Pervasive developmental disorders categories		Number of persons
F 84.0	Childhood autism	267
F84.1	Atypical autism	57
F 84.2	Rett's syndrome	24
F84.3	Other childhood disintegrative disorders	18
F 84.4	Overactive disorder associated with mental retardation and stereotyped movements	30
F84.5	Asperger's syndrome	44
F84.8	Other pervasive developmental disorders	19
F84.9	Pervasive developmental disorder, unspecified	650
Total		1109

Table 3. View the number of registered people with pervasive developmental disorders in Croatia, according to ICD-10.

The prevalence of PDDs in the overall population of the Republic of Croatia is about 2-3/10 000, while in children (population aged 0-18) ca. 1/1000, with three times higher incidence in boys. In Register we see increase (2.6x) number of registrated person with ASD in last seven years (304 registrated person until 01.01.2005. and 792 after that date). The largest number of persons with PDDs, namely 759 (70%), belong to the 5–19 age group (Table 4). Primorsko goranska county and City of Zagreb number the highest prevalence in childhood at just above 1/1000.

County of residence	Age group														Total
	0-4		5-9		10-14		15-19		20-29		30-39		40+		
	m	f	m	f	m	f	m	f	m	f	m	f	m	f	
BJELOVARSKO-BILOGORSKA	0	2	4	3	3	2	7	3	2	1	0	0	0	0	27
BRODSKO-POSAVSKA	0	0	10	1	13	4	9	3	4	5	3	1	1	0	54
DUBROVAČKO-NERETVANSKA	2	1	6	0	10	0	0	2	5	3	1	0	0	0	30
GRAD ZAGREB	12	4	48	17	45	11	28	15	33	13	13	5	11	3	258
ISTARSKA	4	0	13	2	13	2	4	5	6	2	5	0	2	1	59
KARLOVAČKA	0	0	7	0	6	1	2	1	4	0	1	0	0	0	22

County of residence	Age group														Total
	0-4		5-9		10-14		15-19		20-29		30-39		40+		
	m	f	m	f	m	f	m	f	m	f	m	f	m	f	
KOPRIVNIČKO-KRIŽEVAČKA	1	0	7	0	1	0	4	1	3	0	0	0	0	0	17
KRAPINSKO-ZAGORSKA	1	0	4	0	8	2	9	5	6	1	1	0	1	1	39
LIČKO-SENJSKA	1	0	2	0	1	0	1	0	2	0	0	0	0	0	7
MEDIMURSKA	0	0	10	0	2	3	1	2	2	2	0	0	1	0	23
OSJEČKO-BARANJSKA	1	0	20	3	18	3	6	5	12	6	1	3	2	1	81
POŽEŠKO-SLAVONSKA	0	0	0	0	2	0	1	1	0	1	0	0	0	1	6
PRIMORSKO-GORANSKA	0	2	18	7	24	3	15	4	6	2	2	0	1	0	84
SISAČKO-MOSLAVAČKA	0	0	4	3	8	0	7	1	2	4	1	0	0	0	30
SPLITSKO-DALMATINSKA	7	0	21	4	33	9	18	6	23	8	3	7	8	0	147
ŠIBENSKO-KNINSKA	0	2	5	3	8	1	4	1	7	2	3	1	0	0	37
VARAŽDINSKA	2	0	8	2	6	1	1		6	3	0	0	0	0	29
VIROVITIČKO-PODRAVSKA	1	0	4	1	4	1	1	0	1	2	0	0	0	0	15
VUKOVARSKO-SRIJEMSKA	1	0	10	3	7	1	4	2	5	2	1	0	1	1	38
ZADARSKA	0	0	17	5	7	0	6	3	5	0	3	0	2	0	48
ZAGREBAČKA	0	0	5	2	11	3	8	4	6	5	4	1	1	1	51
Unspecified	0	0	1	0	2	0	0	0	3	0	0	0	1	0	7
TOTAL	33	11	224	56	232	47	136	64	143	62	42	18	32	9	1109
As amended on 5 May 2012															

Table 4. Overview of persons with PDDs (F84) by county of residence, sex and age group.

4. Conclusion

All the above leads to the conclusion that there is a difference between the registered prevalences of PDDs in Croatia and other countries of the world. According to the last available CDC data, global prevalence reaches 6.6 per 1000, while in Croatia the rate is ca. 1 in 1000 children (0-18 age group). This great discrepancy, that is under registration of PDDs, could be explained by numerous factors. One of them could be the phenomenon of *diagnostic substitution*, which was encountered in the USA before 1990 until which time PDDs, as a diagnosis, could not secure children the right to special education. In 1990 the passing of the individuals with Disabilities Education Act was the culmination of a long tradition of state and federal acts promoting the closing of institutions and encouraging state governments to support families in their effort to care for and raise their disabled children in their own homes. Autistic children, especially children with comorbid mental retardation and behavior disorders, who, otherwise,

would have been institutionalized in the past, consequently, started attending local schools and were included in the data on school prevalence. Before passing of the above Act, children were labeled as having mental retardation, learning disabilities, speech or emotional disorders in order to be granted the right to certain services. The prevalence of autism has, after passing of the same act, experienced a continual growth. This could partly be ascribed to the method of funding the education of autistic persons, as well as to granting rights to supplementary services (e.g. whole-year schooling), as defined by the legal amendment. The effects of these factors on the existing estimations are controversial and illustrative of the reason why the educational administrative data presented in some media-covered studies may affect the display of the number of autistic persons [9]. Whether this phenomenon of *diagnostic substitution* currently has occurred in Croatia cannot be established with certainty. A proof in favor of its existence could be the fact that there are a total of 141 persons who have official decisions on special education with autism stated under item Orientation list. On the other hand, according to the same decision on special education, 6961 pupils/high school students with unspecified disorders in verbal communication, 3 888 pupils/students with mental retardation (whereof some 65% have light retardation) and a surprising number of 7 219 with multiple impairments have a right to special education in regular schools. Some 50% pupils/students who exercise the right to special education lack the above item of Orientation list so as to escape stigmatization [3]. Each group potentially includes persons with PDDs. A more accurate prevalence of PDDs in Croatia will be available after following the American example and introducing legal regulations to separate autism as a special disability category and granting corresponding rights to persons with PDDs and their families. One should also be reminded of the need of continual professional training of physicians, special education teachers, psychologists and other professionals in new findings in the areas of diagnostics, therapy and rehabilitation of persons with PDDs. By securing this, the advancement of legislation, diagnostics, IT system and the quality of diagnosis recording, as well as sensitizing the public to equation of opportunities for persons with PDDs, will also contribute to advancing the epidemiology of the above disorders.

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