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## Original Research Article

## Autism in Poland in comparison to other countries



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## ARTICLE INFO

## Article history:

Received 16 January 2015

Accepted 18 March 2015

Available online 22 April 2015

## Keywords:

Autism

ICD-10 F84

Epidemiology

ASD

## ABSTRACT

**Introduction:** In recent years, it has been suggested that the increasing incidence of autism diagnosed in Poland highlights improved diagnostics as well as the recorded increase in morbidity. The precise number of individuals with autism in Poland has not been determined, and current sources are unable to provide unequivocal Polish data.

**Aim:** The aim of this study is to compare the epidemiology of autism-related disorders in Poland with other European countries and the United States.

**Material and methods:** Statistical data provided by the Polish National Health Fund Headquarters in June 2013 and data pooled from international journal articles were analyzed in detail.

**Results and discussion:** The National Health Fund reported that 13 261 individuals up to 18 years of age received health services for autism and related disorders in Poland in 2012. This is a prevalence rate of 3.4 cases per 10 000 individuals. Incidence rates vary in different Polish regions, with the highest rates recorded in the following voivodships: warmińsko-mazurskie (6.5 cases per 10 000 individuals), śląskie (5.0), and pomorskie (4.6). The provinces with lowest rates were podlaskie (2.1), małopolskie (1.9), zachodniopomorskie (1.9), and łódzkie (1.8). These rates are far lower than those in European countries (20 per 10 000) and United States (200 per 10 000) epidemiological surveys.

**Conclusions:** Information on the prevalence of autism in Poland and in the world remains unclear and imprecise. This results from global differences in diagnostic criteria. There is urgent need to develop global standards for the diagnosis of autism in children.

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## 1. Introduction

The term "autism" was introduced in 1911 by Paul Eugene Bleuler<sup>1</sup> as one of the basic symptoms of schizophrenia. He defined autism as "a withdrawal from the outside world and a predominance of the inner life." The discernment of autistic children as a separate diagnostic category was established by Leo Kanner in 1943.<sup>2</sup>

Asperger's published research<sup>3</sup> described the behavior of boys with peculiar social issues such as avoiding eye contact, poor facial expression and gesticulation, engagement in repetitive and stereotyped movements and tongue clicking. These boys had well-developed memory but a narrow range of interests. However, it was not until 1980 that the American Psychiatric Association included autism in the list of pervasive developmental disorders (PDDs). In 1993, the World Health Organization further distinguished atypical autism and Asperger's syndrome from the previously recognized autism spectrum.

Currently, autism spectrum disorders (ASDs) are a set of complex neurological developmental disorders which include autistic disorder, Asperger's syndrome and PDDs not otherwise specified.

The criteria for diagnosing autism and ASDs are specified in the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) by the WHO,<sup>4</sup> and in the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) by the American Psychiatric Association.<sup>5</sup>

The ICD-10 classification enables precise diagnosis of disorders. Thus, it allows epidemiological analysis of both the number of treated patients and the services provided to groups of patients with the same diagnosis. In the ICD-10 classification ASDs are coded to F84, which include childhood autism coded to F84.0 (DSM-IV 299.00 Autistic Disorder), Asperger's syndrome coded to F84.5 (DSM-IV 299.80 Asperger's disorder), as well as atypical autism coded to F84.1. Codes F84.8 and F84.9 refer to PDDs not otherwise specified (DSM-IV 299.80 PDD-NOT).

The ICD-10 classification defines childhood autism as a PDD that manifests itself in behavioral dysfunctions. These are characterized by problems with social communication, qualitative communication abnormalities and repetitive, limited and stereotyped patterns of behavior, interests and activity.<sup>6,7</sup>

Until recently, autism was diagnosed by middle childhood, especially when a child exhibited speech delay.<sup>8</sup> Although retrospective studies suggest that most parents identify the first signs of autism in their children as late as 18 months of age,<sup>9,10</sup> certain symptoms of autism, such as impairment in social attention or lack of smiling, can be identified in the first year of life.<sup>11</sup> Studies have shown that although autism can be reliably diagnosed between the 1st and the 2nd year of life, the diagnosis of a wider autistic spectrum is more reliable at a later age.<sup>8,12,13</sup>

## 2. Aim

The aim of this study is to assemble available information on the prevalence of autism in Poland, with particular emphasis

on the Warmia and Mazury region. Our immediate intention is to then provide the Polish autism prevalence data to worldwide bases.

## 3. Material and methods

### 3.1. The criteria for autism diagnosis in Poland

Diagnosis of autism in the Polish National Health Service is compatible with the ICD-10 classification. In addition, it is extended to differential diagnosis based on a multidisciplinary diagnostic model which includes neuroimaging in the neurological tests, and assessment of endocrine, genetic and laryngologist-phoniatric tests. Psychiatric IQ evaluation studies are conducted under the Leiter scale, assuming that the normal condition requires 70–107 points, and 90–104 points on the Wechsler scale.

### 3.2. Data sources

The 2012 data on Polish patients diagnosed with F84 (PDDs) came from National Health Fund Headquarters (Polish: Narodowy Fundusz Zdrowia – NFZ), and 2006–2011 data for Warmia and Mazury province were obtained from the Specialist Children's Hospital in Olsztyn and the Office of the Warmia and Mazury Voivodship. In addition, all available literature on the frequency of autism in European countries and the United States was reviewed.

Statistical studies covered all 16 Polish provinces throughout its 312 685 km<sup>2</sup> dominion. The 31st of December 2012 population recorded 38 533 299 inhabitants in the following voivodships: mazowieckie – 5 301 760, śląskie – 4 615 870, pomorskie – 2 290 070, warmińsko-mazurskie – 1 450 697, podkarpackie – 2 129 951, wielkopolskie – 3 462 196, lubelskie – 2 165 651, dolnośląskie – 2 914 362, kujawsko-pomorskie – 2 096 404, małopolskie – 3 354 077, lubuskie – 1 023 317, łódzkie – 2 524 651, świętokrzyskie – 1 273 995, zachodniopomorskie – 1 721 405, podlaskie – 1 198 690, and opolskie – 1 010 203. The number of infants born between 1994 and 2012 were registered as children aged 0–18 on 31 December 2012, and these numbered 7 531 582.

## 4. Results

Fig. 1 shows the total number of patients throughout the provinces of Poland and the rate in parentheses of those diagnosed under F84 who received medical services in 2012.

The highest rates of children with autism determined by analytic data were as follows: warmińsko-mazurskie voivodship (6.5 cases per 10 000 individuals), śląskie voivodship (5.0), and pomorskie voivodship (4.6); and the provinces with lowest rates were podlaskie voivodship (2.1), małopolskie voivodship (1.9), zachodniopomorskie voivodship (1.9), and łódzkie voivodship (1.8). Our results indicate that the largest group of children were aged 0–6, then 7–14, 15–18 and finally adults over 18 years. The frequency of health care used by autistic people decreased with age.

Table 1 shows the number of people with PDDs treated in warmińsko-mazurskie voivodship between 2006 and 2011.



Fig. 1 – Number of children (0–18 years) treated and ratio (in parentheses) diagnosed with primary ICD-10 F84, and granted medical benefits in Poland in 2012.

Table 1 – Number of patients with the developmental disorder F84 treated in the warmińsko-mazurskie voivodship in 2006–2011.

Year	Number of patients			Rate of F84 patients per 10 000 individuals	First time treated patients 0–18 years old, %
	Total	0–18 years old	0–18 years old, first time treated		
2006	94	90	31	0.7	33.0
2007	72	64	27	0.5	38.9
2008	222	194	41	1.6	21.6
2009	286	272	91	2.0	32.5
2010	306	283	67	2.1	23.5
2011	216	194	39	1.5	19.9

Source: Office of Warmia and Mazury Voivodship.

**Table 2 – Prevalence of ASD (F84) and autism (F84.0) in children in the United States over the last 50 years.**

Year	Age, years	Rate of ASD <sup>a</sup>	Data source
1962–1967	3–12	0.7 <sup>b</sup>	Treffert <sup>14</sup>
1985	2–18	3.26 (1.16 <sup>b</sup> )	Burd et al. <sup>15</sup>
1984–1988	8–12	4	Ritvo et al. <sup>16</sup>
1996	3–10	34	Yeargin-Allsoop et al. <sup>17</sup>
1998	3–10	67 (40 <sup>b</sup> )	Bertrand et al. <sup>18</sup>
2000	8	67	CDC Report <sup>19</sup>
2002	8	66	CDC Report <sup>20</sup>
2006	8	90	CDC Report <sup>21</sup>
2008	8	113	CDC Report <sup>22</sup>
2011–2012	6–17	200	Blumberg et al. <sup>23</sup>

<sup>a</sup> The numbers are given as number of ASD (F84) cases per 10 000 individuals.

<sup>b</sup> Childhood autism (F84.0).

This indicates that the number of people treated, and children diagnosed with F84 aged 0–18 years increased in 2006–2010. Similarly, the rate of treated individuals per 10 000 increased from 0.7 to 2.1.

However, it is noteworthy that deviations from this trend were recorded in 2007 and 2011. In 2007, the number of treated patients and treated ratio were the lowest at 72 and 0.5, respectively.

The Polish patients diagnosed with F84 were compared with literature data on patients in the United States and selected European countries.

Table 2 shows the prevalence of ASDs (F84) and autism (F84.0) in children in the United States between 1962 and 2012. Although the children's ages ranged from 3 to 18, most data refer to children aged 8 years, and it can generally be stated that the incidence of ASD experienced an increasing trend ranging from 0.7 to 200 per 10 000 in 1962–1967 and 2011–2012, respectively.

This alarming increase in autism and ASDs incidence is also apparent in the United Kingdom. Table 3 summarizes the data of children with autism and ASDs in 1964–2004, where the prevalence of this disease increased from 4.1 to 157 cases per 10 000 children. Table 4 highlights the upward trend in autism and ASDs patients in other European countries, and although that data does not apply to current years, it provides illuminating determinant factors in comparison with other countries per 10 000 population. In contrast, the relatively lowest rates of autism and ASDs were noted in Sweden (5.1 in

**Table 3 – Prevalence of ASD (F84) and autism (F84.0) in the United Kingdom in 1964–2004.**

Year	Age, years	Rate of ASD <sup>a</sup>	Data source
1964	8–10	4.1 <sup>b</sup>	Lotter <sup>24</sup>
1970	0–14	4.9 <sup>b</sup>	Wing and Gould <sup>25</sup>
1995	1–4	7.8 <sup>b</sup>	Powell et al. <sup>26</sup>
1999	5–15	26.1 <sup>b</sup>	Fombonne <sup>27</sup>
2003–2004	5–9	157	Baron-Cohen et al. <sup>28</sup>
2003–2004	9–10	116	Baird et al. <sup>29</sup>

<sup>a</sup> The number of ASD cases per 10 000 individuals.

<sup>b</sup> Childhood autism (F84.0).

**Table 4 – Prevalence of ASD in other European countries.**

country, year	Age, years	Rate of ASD <sup>a</sup>	Data source
Sweden, 2009	0–8	5.1	Fernell and Gillberg <sup>31</sup>
Finland, 1979–1994	3–18	12.2	Kielinen et al. <sup>32</sup>
Iceland, 1994–1998	0–18	120.1	Saemundsen et al. <sup>33</sup>
France, 1992	0–18	4.9	Fombonne and Mazaubrun <sup>34</sup>

<sup>a</sup> The number of ASD cases per 10 000 individuals.

2009) and France (4.9 in 1992). Significantly higher rates were recorded in Iceland (120.1 in 1998) and Finland (12.2 in 1994). The growing trend in autism and ASDs was also confirmed in Germany. The trend reveals that the number of autism and ASDs cases in the country between 2000 and 2005 ranged from 3.94 to 5.13 per 100 000 (0.39–0.51 per 10 000) children.<sup>30</sup>

## 5. Discussion

Epidemiological surveys of autism were instituted by Lotter in England (1996)<sup>24</sup> and then conducted in a number of countries.

Although all previous surveys had focused on a category-diagnostic approach to autism based on different criteria, it was assumed therein that autism covers severe problems with communication skills and language, social exclusion and limited and stereotyped patterns of behavior, interests and activity.

Recent studies on the prevalence of developmental disorders and ASDs (F84) provide strong evidence that they are much more frequent than previously speculated.<sup>29,35–37</sup>

These two facts indicate that reported global data on autism and ASDs prevalence are inconsistent in their methodology, the time of their performance and the age of the children diagnosed.

This publication is the first to present the current Polish system of autism diagnosis, and this system does not entirely correspond with global criteria.

How imperfect is our current national system? This question is answered in our further discussion. The care of autistic Polish children and their family protects NFZ and educational organizations and non-governmental institutions. Since no precise standard of care has been prescribed, Poland does not have homogeneous current diagnostic criteria. NFZ classifies each developmental disorder as a disease under ICD-10 F84. Healthcare funds are required to report monthly on benefits accepted under NFZ rules. The NFZ then creates a database of ASDs epidemiology from these computerized reports. Medical entities are further required to furnish annual reports to Governors who collect hospital and clinic data to generate their own report tables in individual years.

Inequalities in determining treatment eligibility for children with autistic disorder in the Polish system are highlighted as follows. According to data published in Report 2000,<sup>38</sup> autism affects approximately 10 000 children and young people and several thousand adults in Poland. However, the SYNOPSIS Foundation<sup>39</sup> estimates that autism and related developmental disorders directly affect more than 30 000 Polish children and adults. Because of these discrepancies and

the limited classification of diseases (NFZ classified only F84.0), it is almost impossible to calculate the precise number of children with autism in Poland.

Since available data are consistent with results of the Fombonne<sup>36</sup> comprehensive report from 43 analytic surveys published between 1966 and 2008 which indicated that global autism prevalence is approximately 20 cases per 10 000 individuals, and the ASDs rate is 60–70 cases per 10 000 individuals, it can be generally be accepted that the overall Polish incidence of autism has an increasing trend.

However, it is necessary to accept the Report of the European Commission<sup>40</sup> to consider this increase fully credible with numerical assessment and to begin searching for etiological causes of the disease, because the report states that the European Union lacks adequate and precise tools to determine autism prevalence.

It is noteworthy that increased autism awareness and changes in the diagnostic criteria were two main reasons for the creation of the label “autism epidemic.”<sup>41,42</sup>

Due to the specific methodological limitations, the high ASD rates in the European Union and the United States in recent years cannot be used to obtain the absolute number of people affected with autism problems. In summary, their report assesses the prevalence of classic autism in the European Union at the level of 3.3–16.0 cases per 10 000 individuals, but these numbers would certainly increase to an estimated range of between 30 and 63 in 100 000 individuals when the complete ASD is considered.

## 6. Conclusions

1. Information on the prevalence of autism in Poland and in the world remains unclear and imprecise. This results from global differences in diagnostic criteria. In addition, a further reason for the different prevalence rates reported throughout Poland is the varied access to specialist health services available in the different provinces.
2. There is an urgent need to develop global standards for the diagnosis of autism in children with respect to their age, genetic, environmental and nutritional conditions.
3. Normalized data on the occurrence of autism in children in different regions of the world, and the reasons for the occurrence, can form the basis for development of homogeneous standards for diagnostic, therapeutic and prophylactic treatment.

## Conflict of interest

None declared.

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