Chapter

The Prevalence of Autism Spectrum Disorder in Europe

Rosemarie Sacco, Nigel Camilleri, Judith Eberhardt, Katja Umla-Runge and Dorothy Newbury-Birch

Abstract

This chapter set out to present a comprehensive review on the prevalence of autism spectrum disorder (ASD) among 5–18-year-olds living in Europe. The review was based on studies published between 2015 and 2020. Separate meta-analyses were conducted for population studies and register-based studies to determine the random effects pooled prevalence rate (REPPR) for ASD. The European REPPR for ASD among young people was estimated at 0.8% based on register-based studies and 1.4% based on population. Comparative analysis was carried out to identify trends of prevalence rates across countries, gender, and level of education. The prevalence among primary school children was four times that of secondary school children. A male: female ratio of 3.5:1 was obtained. A range of challenges toward young people with ASD are portrayed, including diagnostic limitations, poor awareness on ASD, and socioeconomic inequality. Nationwide screening, early intervention services, and further research on gender and culture-specific presentations are recommended.

Keywords: autism, prevalence, Europe, children, adolescents

1. Introduction

Autism is a neurodevelopmental disorder characterized by persistent and pervasive deficits in social interaction and communication, as well as restricted repetitive behaviors [1]. This definition of autism encapsulates a greater range of presentations when compared with the definition provided by the Diagnostic and Statistical Manual (DSM)-III [2], which listed criteria such as "perversive lack of responsiveness to other people" and "gross deficits in language development." This shift has undoubtedly led to an increase in prevalence rates, ranging from 21 in 10,000 in 1979 [3] to a global figure of 1 in 100 [4] more recently (are there quotes for 1 in 66 too?).

The prevalence is the proportion of individuals in a population with a disease at a specific point in time. This rate is obtained from epidemiological studies such as register-based and population studies. The latter refers to studies that assess all the individuals sampled from a target population to determine the prevalence in that population. On the other hand, register-based studies use registers to determine the number of individuals who are registered with a diagnosis in the target population. Prevalence studies on autism give an indication of the condition's impact in terms of

the number of cases, as well as socioeconomical costs. They also indicate the level of awareness, identification, and supportive services offered to the population in question. These data should serve as a foundation from which policymakers plan service development to ensure that the present needs of the population are met [5].

This chapter presents a systematic review on the prevalence of autism among 5–18-year-old young people in Europe. The focus on Europe was intended to obtain a more in-depth understanding among European countries with similar sociodemographic characteristics. Including data from multiple continents may have been interesting to evaluate the entire body of evidence, increase statistical power, and highlight differences in the distribution of autism across different continents. However, adequate clinical and research competence for autism is still developing in low- and middle-income countries [4]. With considerable variation in sociodemographic factors, awareness, and diagnostic expertise [6], there is a risk of prevalence rates being greatly underestimated in certain parts of the world, in fact considerable variation in prevalence rates has been reported across different regions [7, 8]. Cross-national comparisons across countries with very different levels of awareness and expertise on autism may therefore be inappropriate. Furthermore, an overall global prevalence rate may not accurately reflect the situation in Europe.

The review gives a comprehensive appraisal of the eligible prevalence studies, which were published between 2015 and 2020. The short and recent time frame was intended to draw a clearer picture on the current prevalence situation. Previously published meta-analyses have estimated the prevalence of autism by including studies dating back to 1966 [8]. While including studies from the distant past may improve the statistical power, the pooled prevalence rates may not be generalized to the current situation and not reflect the reported rise in prevalence over time [4]. Moreover, the chapter presents cross-national comparisons of prevalence rates to ascertain trends across countries, gender, and level of education. These were used to draw inferences on present barriers to identification of autism, such as stigma, poor diagnostic systems, and unequal diagnostic sensitivity across gender and age. Methodological and diagnostic factors that may under- or overestimate the true prevalence of autism are also discussed.

2. Methodology

2.1 Literature search and search strategy

PubMed and Google Scholar were used to review the existing literature and identify a gap in the literature on the prevalence of all mental disorders among children and adolescents in Europe. A search on Prospero [9] confirmed that there were no reviews registered in this area, so a protocol for this study was then registered there (Registration number: CRD42020210451). A search strategy was developed using the SPIDER model and conducted on MEDLINE, Embase, and PsychInfo on the 30th April 2020. The search was limited to studies with a title and abstract in English.

2.2 Eligibility criteria

Studies were considered eligible if they were original epidemiological studies that determined the prevalence of a mental disorder as defined by ICD-10, DSM-IV, or DSM-V criteria, among 5–18-year-olds in European countries. Studies were excluded

if they did not include the general population, for instance, by focusing on minority groups, or if they were published before 2015.

2.3 Study identification and selection procedure

Studies found by the search were screened independently by title and abstract by RS. The studies that met inclusion criteria were screened independently by full text by RS. DNB screened 20% of all the studies at title/abstract and at full text review stage. Reference lists and gray literature were searched manually by RS.

2.4 Quality analysis

The reliability, validity, and bias of each eligible study were assessed using the Appraisal Tool for Cross-Sectional Studies (AXIS) [10] and the Risk of Bias in Prevalence Studies Tool (RBPS) [11].

2.5 Data analysis

Only the eligible studies that estimated the prevalence of autism were included in the analysis for this chapter. Median and average estimates and ranges of autism prevalence rates for young people in Europe were determined. Comprehensive meta-analysis software [12] was used to analyze prevalence data from the eligible studies. A random effects model was used to determine the random effects pooled prevalence rate of autism in Europe. Prevalence rates obtained from population and register-based studies were analyzed separately since the two study types have non-homogeneous populations, and there may be significant discrepancy of factors at many levels of the variable of interest. Data from the two study designs were therefore analyzed separately to avoid Simpson's paradox [13]. The standardized residual values (SRV) were evaluated from the forest plots and a cutoff of +/−3 at 95% confidence interval was used to identify outliers [14].

Cross-national prevalence comparisons were made across countries, gender, and level of education. The latter was done to compare prevalence rates between young children who attend primary school, to older children who attend secondary school. Prevalence rates were not compared according to specific age groups since the eligible studies presented results for a mixed range of age groups, which were incomparable. The contribution of specific cofactors to heterogeneity could not be evaluated through a meta-regression analysis because results would be insignificant due to the low number of eligible studies [15].

3. Results

Nine eligible studies were identified that provided prevalence estimates for 11 European countries as illustrated in **Table 1**. The AXIS and RBPS tools indicated low-level bias among all the eligible studies.

3.1 The Prevalence of Autism among 5–18-year-olds in Europe

Based on the eligible studies, the prevalence ranged from 0.3% in the West Pomeranian and Pomeranian regions of Poland to 14.3% in Romania (**Figure 1**). The median prevalence was 1%, and the average prevalence was 1.97%.

Author Year	Region [Nationwide]	Study Design (Register based study (RBS)/ population study (PS))	Sample Number (% Male, % Females)	Age Range (Years)	Level of Education			Diagnostic Classification	Risk of Bias (ROB) Scores ** (AXIS, RBPS)
					Primary	Secondary	Both		
Boilson, A.M. et al. 2016.	Ireland (Galway, Waterford, Cork) [No]	PS	7951 (54%, 46%)	6–11	Yes	No	No	DSM-IV TR	2, 1
Budisteanu, M. et al. 2017.	Romania [Yes]	PS	NA	7–9	Yes	No	No	DSM-IV TR	7, 3
Delobel-Ayoub, M. et al. 2020.	Denmark, Finland, Iceland, South West France, South East France [Yes]	RBS	NA	7–9	Yes	No	No	ICD-10	3, 3
Elberling, H. et al. 2016.	Denmark (Copenhagen) [No]	PS	1585 (52%, 48%)	5–7	Yes	No	No	ICD-10	0, 1
Lesinskiene, S. et al. 2018.	Lithuania (Nationwide) [Yes]	PS	526 (54%, 41%)	7–17	Yes	Yes	Yes	ICD-10	1, 0
Morales-Hidalgo, P. et al. 2018.	Spain (Tarragona) [No]	PS	1449 (50%, 50%)	10–12	Yes	No	No	DSM-V	3, 1
Narzisi, A. et al. 2018.	Italy (Pisa) [No]	PS, RBS	10,138 (52%, 48%)	7–9	Yes	No	No	DSM-V	1, 2
NHS 2018.	England [Yes]	PS	6219 (50%, 50%)	5–16	Yes	Yes	Yes	ICD-10	2, 1
Skonieczna-Żydecka, K. et al. 2017.	Poland [No]	RBS	2514 (81%, 19%)	8–16	Yes	Yes	Yes	ICD-10	2, 2

**Ages were estimated from additional sources showing the age groups of children in the mentioned school grades [16, 17].*
***Scores for ROB reflect the number of elements in each tool that indicate potential for bias. AXIS has a total of 20 items whereas RBPS has 10 items.*

Table 1.
Eligible studies and their characteristics.

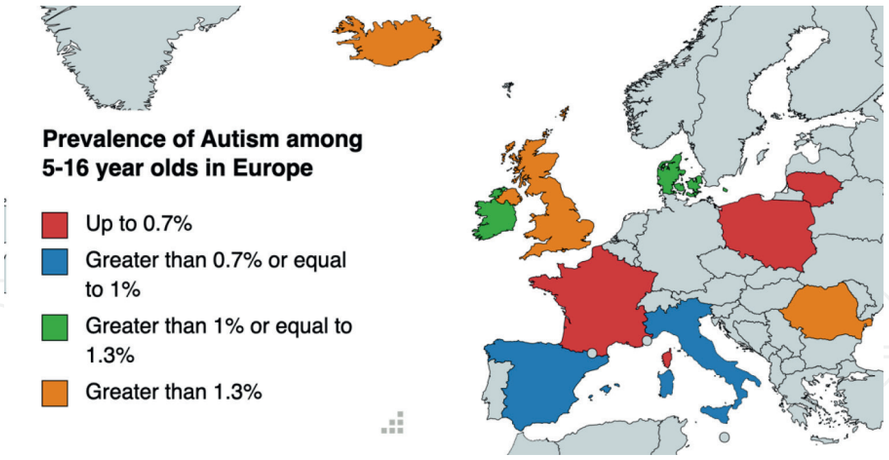

Figure 1.
The prevalence of autism among 5–18-year-old young people in Europe.

3.2 Prevalence rates from different study designs

One study [18] used both register-based and population study methods, thereby providing two prevalence rates for autism in Italy (Pisa). Two other studies were register-based studies, and six were population studies.

3.3 Prevalence rates from register-based studies

Three studies used registers to determine the prevalence. These studies estimated the prevalence of Pisa, West Pomeranian and Pomeranian region of Poland, South East and South West of France as well as the nationwide prevalence of Denmark, Finland, and Iceland. The prevalence of autism from these studies ranged from 0.3% in the West Pomeranian and Pomeranian regions of Poland to 2.7% in Iceland. There was a discrepancy of 2.4% between the highest and lowest prevalence rate. The median of these rates was 0.8%, and the average was 1%. **Figure 2** shows a forest plot with the REPPR of young people with a diagnosis of autism being 0.8% (95%CI: 0.5%–1.4%, I^2 = 99.5%). Although the prevalence reported in Iceland was much higher than that reported in other regions, its SRV was 1.80 and was therefore not considered to be an outlier.

3.4 Prevalence rates from population studies

Seven population studies with a pooled sample size of 33,579 individuals estimated the prevalence of autism in European countries. Three studies determined the

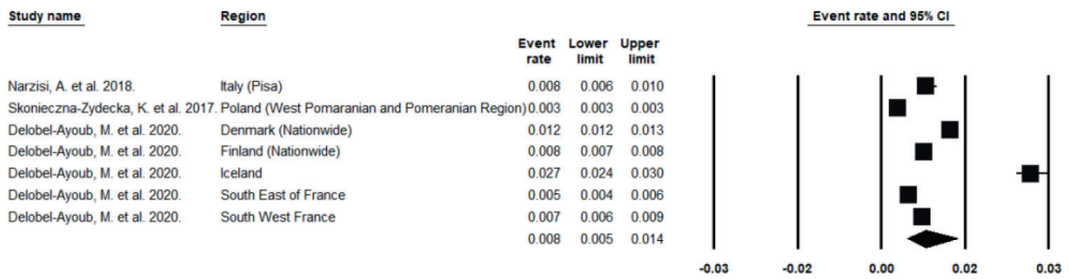

Figure 2.
Forest plot of the prevalence rates of autism among young people in Europe from register-based studies.

nationwide prevalence in Romania, Lithuania, and England. Another four studies determined the prevalence in Pisa (Italy), Galway, Waterford, and Cork in Ireland, Tarragona in Spain, and Copenhagen in Denmark. The prevalence rates ranged from 0.4% Lithuania to 14.3% in Romania. The prevalence rate estimated in Romania is much higher when compared with other prevalence rates; however, the SRV is 1.44. The median prevalence was 1.2%, and the mean was 2.9%. The REPPR of autism among young people in Europe based on population studies was estimated at 1.4% (CI: 5.4%–0.4%, I2 = 99.7%) as shown in **Figure 3**.

3.5 Prevalence of autism across level of education

Seven of the eligible studies estimated the prevalence of primary school children, whereas two estimated the prevalence of secondary school children. These are depicted in **Figure 4**. The prevalence among primary school children ranged from 0.8% (95% CI: 0.6%–1.0%) in Pisa to 14.3% (95% CI: 13.6–15.1%) in Romania. The median prevalence rate for primary school children was 1.2%, and the mean was 3%. A REPPR for primary school children of 1.6% (95%CI: 0.4%–6.1%, I^2 = 95.5%) was obtained. The prevalence of autism among secondary school students ranged from 0.1% (95%CI: 0.00%–0.4%) in Lithuania to 1.2% (95% CI: 0.9%–1.7%) in England. A REPPR for secondary school children of 0.4% (95% CI: 0.00%–4.5%, I^2 = 92.2%) was obtained. The REPPR among primary school children was four times greater than that estimated for secondary school children. I2.

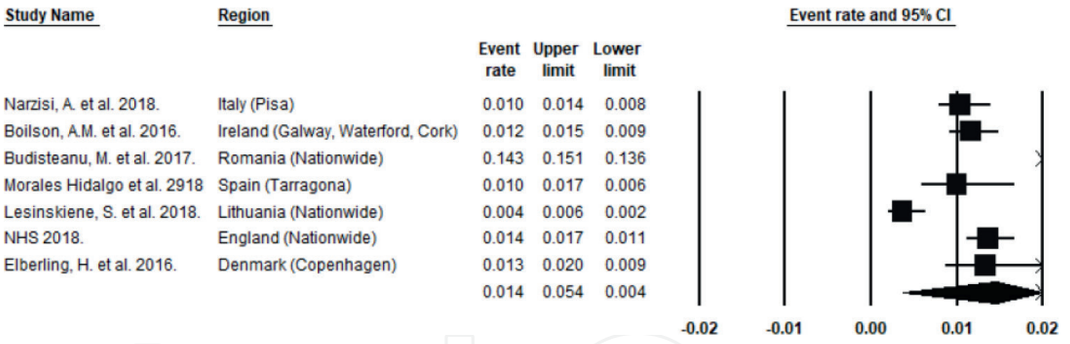

Figure 3.
Forest plot of the prevalence rates of autism among young people in Europe from population studies.

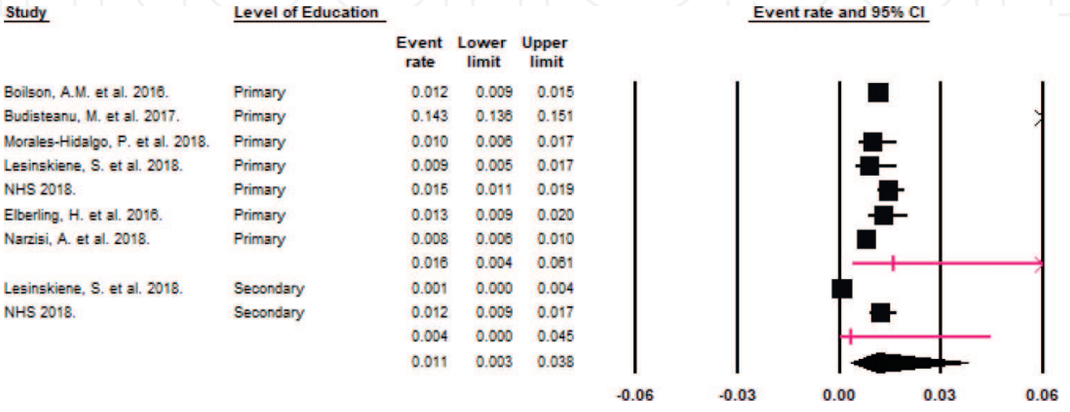

Figure 4.
Forest plot showing the prevalence rates of autism among young people in Europe with the level of education as the unit of analysis. The lines in magenta represent the REPPR for primary and secondary school children.

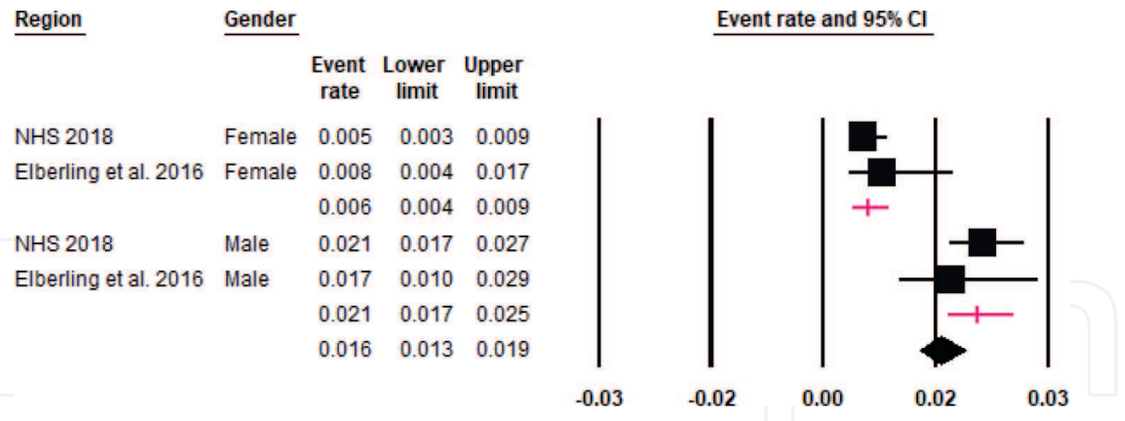

Figure 5.
Forest plot showing the prevalence rates of autism among young people in Europe with gender as the unit of analysis. The lines in magenta represent the REPPR for females and males.

3.6 Prevalence of autism across gender

Only two studies provided separate prevalence rates for males and females (**Figure 5**). Based on these, the REPPR of autism is 0.6% (95%CI: 0.4%–1.7%, I^2 = 0%) and 2.1% (95%CI: 1.7%–2.5%, I^2 = 0%) for young females and males respectively. Based on these figures, the REPPR of males is 3.5 times greater than that in females.

4. Discussion

This chapter provides a comprehensive review of the original prevalence studies on autism in European countries published between 2015 and 2020. Factors that may have influenced the estimation of prevalence rates are discussed below.

4.1 Study designs

Register-based studies use administrative databases in educational or health systems to determine the number of individuals who have obtained a diagnosis in the target population. These studies are limited because they only include individuals who actively sought help from professionals and gave consent for their diagnosis to be reported . Since autism includes a range of phenotype variants, milder forms may be missed, so prevalence rates may be underestimated by register-based studies. These factors may contribute to the lower prevalence rates estimated among register-based studies when compared with population studies.

When considering the register-based studies, the prevalence ranged from 0.3% in Poland to 2.7% in Iceland. Reasons for the low prevalence documented in Poland may include both under-diagnosis and under-reporting. At the time of the study, in Poland, there were non-standardized diagnostic systems [19], poor levels of awareness, and high levels of stigma, which could prevent parents and young people from seeking help [20]. Moreover, there were no enforcements for reporting diagnosed cases of autism [20]. These factors may have contributed to an underestimation of the prevalence rates. Interestingly, these factors were reversed when the study in Iceland was conducted. In fact, the study occurred after improved awareness and access to autism diagnostic services [21], which were upgraded to formally diagnose high

functioning autism [22]. These factors may have improved the accuracy of autism identification, bringing about a higher estimation.

Population studies assess a sample of individuals from the target population. Some of these studies use gold-standard diagnostic tool on all the participants as seen in the study conducted in England [23]. Since diagnostic assessments are very time-consuming and costly, most studies use a multistage approach whereby the sample is first screened and a diagnostic assessment is carried out on individuals who scored up and a proportion of individuals who did not score up, to confirm whether criteria for a diagnosis estimated the prevalence rate.

Screening tools used in the eligible studies include EDUTEA [24], CAST [25], SCQ [26], and the SDQ [27]. Diagnostic tools used by the eligible studies include the ADI-R [28], ADOS [29], and DAWBA [30]. Although these are standardized tools, their accuracy depends on the proficiency of the data collectors administering them [6]. Moreover, when these tools are used within clinical or educational services, clinicians may be more inclined to give a diagnostic label to enable access to services [6].

Another difficulty is that screening tools do not have a 100% sensitivity rate, and there are no clear guidelines for how to combine conflicting results from multiple informants. As a result, true cases may be missed, and prevalence rates may be underestimated. A further limitation is that population studies have a variable participation rate. The participation rate of the eligible studies ranged from 49.5 to 100% in the screening phase and from 14 to 100% in the diagnostic phase. Although statistical weights were applied to account for participation rates across each study phase, there remains the possibility for participation to be associated with having a diagnosis [6] or with good mental health [31], which would bias the prevalence rates upward or downward.

4.2 Diagnostic criteria

The two main gold standard classification systems used in Europe are the Diagnostic and Statistical Manual (DSM) and the International Classification of Diseases (ICD). The editions currently being used are the DSM-5 [32] and the ICD-11 [33], which started to be put in use in 2013 and 2022 respectively. The eligible studies in this review made use of DSM-IV TR [34], DSM-5 [32], and ICD-10 [35]. The diverse diagnostic criteria may partly contribute to the varied prevalence rates obtained. Studies have shown that DSM-5 criteria result in fewer individuals diagnosed with autism when compared with DSM-IV TR [36–38]. Moreover, another study has shown that among individuals diagnosed with autism on ICD-10, only 58% met DSM-5 criteria [39]. Furthermore, ICD-10 and DSM-IV distinguish between different autism subtypes, whereas DSM-5 considers a single spectrum. The study carried out in Lithuania [40] was the only eligible study in this review to use a restricted case definition of "Autistic Disorder" based on ICD-10. This definition excludes young people with Asperger's syndrome that would meet criteria for autism spectrum disorder in other studies. This limited definition may underestimate the prevalence of autism in Lithuania and further contribute to prevalence discrepancies.

4.3 Culture

Culture may influence behavioral presentations, as well as parents' and clinicians' appraisal of what is considered acceptable and undesirable behavior [41].

The ADI [28] and ADOS [29], which are gold standard diagnostic criteria for autism, were developed in the United States. These include items such as shared eye contact, social smiling, and social interactions that may be characteristic in countries such as Italy, Spain, and England but less so in other countries such as Romania where eye contact may be avoided and interaction may be of a more formal nature [42]. While these examples are undependable, they call for cultural sensitivity in working across cultures. A systemic investigation to determine the extent of variation in autism phenotype across cultures may inform adaptations in scoring autism diagnostic tools [6].

4.4 Age

Most prevalence studies on autism include age groups at which school attendance is compulsory, to support widespread sampling. Moreover, a diagnosis of autism may be validated with robust diagnostic tools by 8 years of age [6]. Although some epidemiological studies have started to include preschoolers, there are limited sensitivity and specificity in the screening tools available for this age group [6]. On the other hand, in older-age groups, there may be improved detection with increased social demands [43], as well as a risk of milder phenotypes getting more easily missed [6]. Autism was first described as a childhood disorder by Kanner in 1943 [44] and continued to be recognized as one until the relatively recent appreciation of its persistence in adulthood [45]. This historical detail may influence the identification of autism at different age groups. In fact, there is still a gap in research and awareness on adults with autism [46], and many adults remain undiagnosed [47]. This may suggest underestimation of prevalence among the older-age groups, producing a higher pooled prevalence for primary school children when compared with secondary school children.

4.5 Gender

In this review, the estimated prevalence of autism was 3.5 times greater for males when compared with females. This is in keeping with findings from other studies [48]. Many theories such as the "extreme male brain" [49] and the "female protective effect" [50] have sought to justify this gender difference. The "extreme male brain" considers autism as an "extreme" of the normal male profile in which systemizing is better than empathizing. The "female protective effect" refers to the notion that females require a greater genetic load to obtain an autism phenotype. However, females have often been excluded from research on autism, which may have resulted in limited sensitivity of diagnostic criteria toward the female autistic presentation [51]. Moreover, there is growing evidence that females are diagnosed later and need a worse presentation when compared with males, to obtain a diagnosis [52]. These data may suggest that gender prevalence discrepancy may be caused by poor detection among females, rather than actual prevalence differences.

4.6 Trends over time

A rising trend in the prevalence of autism has been reported over time. In fact, the estimated pooled prevalence of 1.4% for autism, from population studies published between 2015 and 2020, is considerably higher when compared with the prevalence of 0.2% estimated in the 1990s [53]. This rise may be partly attributed to broader diagnostic criteria, improved study methodologies, and improved knowledge and

detection of autism [54]. Other dynamic risk factors that may increase the actual prevalence of autism may also play a role. These may include advancing parental age [55], improved neonatal care [56], and increased maternal substance misuse [57]. However these environmental factors may not explain the considerable and sudden prevalence rise of autism.

Strengths and limitations.

To our knowledge, this was the first study to provide a comprehensive review of the prevalence of autism among young people in Europe based on recent studies published from 2015. Moreover cross-national comparisons have brought to light several factors that may influence the estimation of autism prevalence rates. While this study makes a positive contribution to the present knowledge on autism prevalence, a number of limitations also need to be acknowledged. Firstly, there is a risk of selection bias since all the studies were identified by one researcher and only 20% of these were checked by another researcher; therefore, some studies may have been overlooked. Another limitation is that prevalence rates could not be compared across various age groups since different original studies group ages differently. An important limitation is that the review only includes nine original studies. This limited further analysis such as a meta-regression analysis that would investigate the effect of various covariates on the prevalence rate estimated. Nevertheless, the data were synthesized comprehensively to elicit aspects relevant to policymakers as well as the research and clinical communities.

5. Conclusion

This was an up-to-date review on autism epidemiology in Europe, estimating a pooled prevalence of 0.8% and 1.4% from register-based studies and population studies respectively. Importantly, this review calls policymakers to develop strategies that aim improve awareness and reduce stigma on autism as these may serve as barriers for individuals with autism to get identified. Furthermore, it calls for further research to determine the extent of phenotype variation across different cultures and gender since present diagnostic tools and criteria may have unequal sensitivity for certain groups. Finally, improving diagnostic sensitivity and developing routine nationwide screening and early intervention strategies may greatly improve the trajectory of individuals with autism.

Conflict of interest

The authors declare no conflict of interest.

Notes/thanks/other declarations

This chapter presents findings from an original systematic review that evaluated the prevalence of mental disorders among young people in Europe. Only aspects of this study that were relevant to autism were presented in this chapter.

The Prevalence of Autism Spectrum Disorder in Europe
DOI: http://dx.doi.org/10.5772/intechopen.108123

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