

Autism Prevalence Information And Diagnosis Processes In Cyprus, Greece And Malta

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Abstract: The current paper follows the thematic review ‘*Autism spectrum disorders without borders: prevalence and diagnosis across the globe*’ aiming to highlight and familiarize readers with the challenges and heterogeneity related to the prevalence, and diagnostic processes of Autism Spectrum Disorders (ASD) from a cross-cultural and diverse geopolitical framework with a focus on Cyprus, Malta, and Greece. The study’s goal was twofold: (a) to document the prevalence and diagnostic processes in the aforementioned geographical areas and (b) to highlight similarities and differences in the prevalence and diagnostic process in ASD. The findings revealed similarities across all countries regarding the diagnostic tools implemented in ASD assessment tools and clinical observations. Some differences were observed in documenting prevalence rates due to methodological heterogeneity in the documentation procedures. Although preliminary, the current findings underscore the importance of research-driven investigations that can lead to larger-scale programs necessary for establishing policy-making and stakeholders’ involvement.

Keywords: ASD, geographical regions, prevalence, diagnosis

Introduction

ASD is recognized as a complex dynamic and heterogeneous disorder. Its onset occurs early in the life of a child.^{1–6} It results from complex neurobiological underpinnings that affect brain circuitry.^{7–11} Converging evidence indicates that a synergy of factors including epigenetic, biological, and environmental parameters interact in complicated mechanisms responsible for clinical etiology and symptomatology.^{9,12,13} ASD affects individuals and their families across the globe regardless of religion, language, and/or socioeconomic background.^{14,15} Although the symptoms of autism surface during the early years of life, identification of symptoms and diagnosis might occur at a later point in a child’s life.^{16–18} Factors related to the diverse onset of the diagnosis are associated with the heterogeneity of symptoms, scarcity of appropriate assessment tools, and lack of awareness regarding the early signs of ASD.^{19,20} Arguably, some of the defining clinical characteristics of ASD involve social-pragmatic challenges, immediate and/or delayed echolalia, late onset of speech development, and difficulty in the changes or routine activities.¹¹ Moreover, comorbid conditions in ASD include cognitive limitations, executive functioning challenges, and academic difficulties.^{1,2,20,21}

Incidence and prevalence refer to the occurrence and frequency of a particular disease/disorder in a specific population (eg, the appearance of new cases) over a given period. Prevalence databases are important because they provide a numerical and population-based “picture” regarding the frequency of a disorder necessary for informing public health policies, interventions, and implementation of professional training programs for optimal service provision for individuals with ASD including underserved populations.^{5,22} Documentation of prevalence across the globe poses challenges. After all, it requires factoring in cultural, linguistic, geopolitical, and socioeconomic parameters. The average figure regarding the global prevalence of ASD is 1 in every 100 individuals, with a ratio of 4:1 males versus females with overall prevalence estimates being 222 per 10,000 children worldwide.^{22,23} Although ASD prevalence across the world is difficult to estimate, converging evidence reveals a remarkable increase in the cases diagnosed every year (Centers for Disease Control and Prevention CDC)² indicating that in 2016 approximately 1 in 54 individuals in the United States presented with the diagnosis of ASD.^{5,22} Notably, limited prevalence data from underserved and minority populations remain underexplored thus necessitating the establishment of examinations and

screening protocols in underserved populations living in remote areas for timely and accurate diagnosis of ASD. Such observations underscore the need for establishing national screening protocols taking into consideration the heterogeneity and diversity of populations with communication disorders including ASD.^{14,22,23}

Overall, although research findings regarding screening, assessment, and management of children with ASD are available in many developed countries (eg, USA, Australia, UK), available findings indicate that in other less developed parts across the globe, identification and assessment management remain unexplored.¹³ Delayed identification of ASD might be related to factors including language and cultural characteristics entwined with each child's idiosyncratic background.^{19–22} Managing developmental disorders warrants timely and accurate identification, sets the foundation for positive outcomes within the multi-disciplinary team context, and requires the interaction and cooperation among members of an interdisciplinary team with speech-language pathologists (SLPs) forming a core professional group in the management of ASD individuals and their families.^{3,12,13} However, it is remarkable that knowledge about clinical practices in the context of speech and language therapy services for individuals with ASD remains limited.²⁴ A recent survey via questionnaires completed by approximately 1135 SLPs from 35 different countries within the school setting context in metropolitan areas revealed that the typical age of diagnosis for ASD was 3 to 4 years. In terms of assessment, remarkable heterogeneity was reported regarding the implementation of standardized batteries for screening and diagnosis of ASD. Specifically, for comprehensive assessment approaches SLPs use both formal and informal assessment measures (when available) which target communication, speech and language social, and pragmatic skills vis-a-vis differential diagnosis methodologies.^{25,26} For linguistic assessment, despite the availability of a plethora of resources, the consensus points towards a heterogeneous picture about cultural biases and implementation of practice-based evidence issues.^{27,28} Nowadays, there are numerous clinical tools clinicians can use when assessing non-English speaking although implementing such tools might compromise generalization and interpretation of the results.²⁹

The current investigation was set to examine ASD prevalence data and diagnostic protocols implemented in three different countries including Cyprus, Greece, and Malta. Furthermore, the investigation documented the similarities and differences across the countries on the variables of focus. The methodology included the gathering of information from diverse resources based on the availability of published data on prevalence, information from the national registries, and reports from Ministries of Education and Health Provision Services respective to each country. In the following sections, the authors present the findings for each country.

ASD in Cyprus

Cyprus is the third largest island located in the Eastern Mediterranean Sea with Greek being the predominant language spoken by the majority of the population comprised of Greek-Cypriots who are speakers of the dialect of Cypriot Greek (CG) classified as a South Eastern variety of Modern Greek.^{30,31} ASD prevalence data in Cyprus remain sparse albeit numerous efforts to document ASD cases as a function of age, severity, and distribution across educational and clinical settings. As of today, there is no official registry of ASD regarding prevalence based on longitudinal long-term incidences documentation. Nevertheless, keen efforts to start documenting ASD cases are undertaken by official governmental bodies including the Committee for the Protection of Humans with Handicaps, the Undersecretary-Department of Social Welfare, the Health Insurance Organization (HIO), and the newly-founded Center of Neurodevelopmental Disorders. A recent large-scale cross-sectional study of children 10,000 within the age range of 5 to 12 years attending schools across various areas across Cyprus, revealed an average prevalence of ASD in approximately 2% of the population with a significant male predominance (80.3%, gender ratio of 4:1) with prevalence being significantly higher in special schools (41.9%) as compared to primary (1.3%) and pre-primary schools (2.7%).³² Information from a published newspaper special report as presented by a member of the Cyprus parliament (MP) (Cyprus Mail 2023 Oct 23)^{33,34} regarding the number of individuals with ASD from 2018 to 2022 the following figures were reported:

1. Information from incoming assessment inquiries for service provision reported by HIO reported that approximately 1,190 minors presented with ASD diagnosed in 2022 with 228 individuals being above the age of 18.
2. Information from the Cyprus Ministry of Health reported that approximately 936 individuals presented with the diagnosis of ASD. According to available information for some but not for all cases, 426 people presented with variable clinical characteristics across the spectrum, and 105 fit the clinical profile of high-functioning ASD profiles.

3. Information from The Cyprus Ministry of Education, Religion and Athletics reported that 858 with a diagnosis of ASD were attending school. Distribution of individuals in different settings reported that 184 children were in special schools, 250 in resource rooms, and approximately 424 followed inclusive education (mainstream).

For diagnosis of ASD, the standard procedure follows the guidelines and measures provided by the International Classification of Diseases (ICD-10),² the Diagnostic and Statistical Manual of Mental Disorders (DSM-V)¹, the Autism Diagnostic Observation Schedule (ADOS)³⁵ And the Modified Checklist Assessment for Toddlers (M-CHAT).³⁶ The diagnosis is given by the child psychiatrist but clinical symptomatology (eg, speech, language, and communication profiles) is managed by an interdisciplinary team. It should be noted that, over the past year a keen effort from several scientists has undertaken the implementation of the first national screening program for ASD. Furthermore, the family service-based program “AKTIDA” is currently providing home-based service to more than 300 pre-schoolers and their families. In 2022 the Cyprus governmental cabinet approved the creation of the National Committee for Autism, aspiring to examine from a multidiscipline framework the deficiencies, shortcomings, needs, and areas of improvement on many issues related to early intervention, education, diagnosis, social welfare, etc of individuals with ASD and their families with an end goal to provide and support a long-term and sustainable strategic plan for the implementation of specific actions.

ASD in Greece

There are two studies on the prevalence of ASD in Greece with both revealing similar results despite methodological as a result of different resources and databases used in the documentation of ASD.^{37,38} Specifically, in the former investigation data were collected based on available information resourced from the Centres for Educational and Counselling Support (KEDASY), an organization responsible for decision-making in service provision for individuals diagnosed with ASD. According to the authors, ASD prevalence overall was reported to be 1.15% (1.83% males, 0.44% females; ratio 4:1) with ranges occurring from 0.59% to 1.50%. The age of diagnosis was approximately around 6;0 years, with girls being diagnosed approximately three months earlier than boys.³⁷ In the second study data provided by the Greek National Health Service Organization for Healthcare Services Provision (EOPYY) with diagnoses based on the ICD-10 codes, a total of 15,706 children ages 2;0–17;0 years were presenting with the diagnosis of ASD (12,380 boys and 3326 girls). The annual prevalence was estimated at 0.94%, ranging from 0.42% to 1.44% as a function of geographic location. Another useful piece of information in this study was about the number of therapies subscribed for ASD children via the Healthcare Services Provision (EOPYY), providing the families with significant support (monthly stipend for each child) for supporting clinical services including speech therapy, occupational therapy, psychotherapy, etc. According to this study during 2021, a total of 6,117,910 intervention therapies were prescribed, 4,844,173 for boys and 1,273,737 for girls.³⁹ The existence of child psychiatric clinics and centers around Greece is of significant help in the recognition and diagnosis of ASD early in life. Diagnosis of ASD occurs only after a clinical evaluation issued by a public or private sector and by an interdisciplinary team consisting of a child psychiatrist and/or child neurologist and/or developmental specialist, psychologist, SLP, and occupational therapist.

For diagnosis of ASD the standard typical procedure is based on the relevant information described in the ICD-10,² and/or the DSM-5,¹ ADOS³⁵, the M-CHAT³⁶, and different other evaluation tools depending on the case comorbidity. For school-age children with ASD, specific health provision agencies include the Centres for Educational and Counselling Support (KEDASY) and the Ministry of Education of Greece which provide services for students with special educational needs and provide support, management, and counseling services. The overarching aim is to promote inclusive education and the most suitable integration of every child into the indicated educational setting. Educational settings for persons with ASD include one of the following:

1. Mainstream education in full-time schooling settings.
2. Inclusion classes running within a mainstream school setting.
3. Special schools.
4. Schools exclusive for students with ASD.
5. Home-based schooling.

There are more than 20 parental associations for ASD in Greece, one of them is on a national scale “Greek Association of Protection Autistic People” (<https://autismgreece.gr/en/>), and the others are functioning on a more local scale, all of them deliver support services families and children. In addition, a Greek Scientific Network exists with main goal the supporting of the research on ASD in Greece and the collaboration between the professionals in this field (<https://autismnet.gr/about-us/>).

Municipalities are mostly established with financial help from the government, Special Creativity Centers for children and adults with disabilities and a large number of individuals with ASD find there the appropriate facilities on an everyday base (<https://ypergasias.gov.gr/en/persons-with-disabilities/>).

ASD in Malta

Malta is a small island located in the central Mediterranean Sea with a population of approximately 401,846 out of which 8% reported presenting with a disability (data based on reports for ages 0 to 18 years of age).^{40,41} Although there is no official data available regarding the incidence and prevalence of autism in Malta sporadic reports suggest ASD affects 1 in 60 children and has a prevalence rate to be approximately 2%.⁴² More recently, in 2021 Malta’s National Autism Strategy 2021–2030 published the following statement:

It has been a long journey, but Malta finally has its first National Autism Strategy and has been collecting input ever since the first formation of the Autism Advisory Council was given its mandate on World Autism Day in 2018.⁴³

Although the findings suggest that service provision in Malta has improved over the last few years, more efforts should be undertaken in certain areas related to diagnosis and prevalence data documentation. Information also indicates that approximately 30% of parents reported being unsatisfied with the diagnostic and optimum clinical management of ASD. Specifically, caregivers and parents of children with ASD in need of early diagnosis reported that although the process was lengthy it was nevertheless thorough, reliable, and well-informed. The diagnosis was reported to be quicker through private professionals.⁴⁴ For services regarding adult cases a different picture emerged with approximately 80% of adult service users receiving their diagnosis during adulthood.⁴³ Support services and referrals for treatment and management of adults with ASD following a diagnosis were restricted, with 91% of service user respondents and 82% of caregivers not having received any services or information after the onset of the diagnosis.^{43–45}

Reportedly, a screening program for 2-year-olds named “Lenti fuq l-iżvilupp ta’ uliedna’ is available to children as young as 18 months.⁴⁶ The Government of Malta provides this service in the sense that parents of children as young as 18 months can capitalize on the opportunity to have their children screened. The overarching goal of the “LENTI” program is to ensure a smooth and easy way for screeners, college staff, and parents alike to monitor the holistic health development of children. The diagnosis is usually placed around the age of 2.0 to 2.6 years, especially for children with robust clinical markers related to ASD symptomatology as compared to children with less severe symptoms usually diagnosed at a later age. The diagnosis of ASD is based on standard criteria that are implemented in numerous countries across the globe based on coding systems according to ICD-10, DSM-5, ADOS, and M-CHAT taking into consideration comorbidity. According to Malta’s first-ever National Autism Strategy adopted by Malta’s Ministry for Inclusion and Social Wellbeing, the ASD Persons’ Act was passed in 2016 yielding, on the one hand, significant support to the rights of children with ASD and advancing the set-up of the Autism Advisory Council on the other hand, in monitoring the implementation of a National Autism Strategy. This act rendered Malta a pioneer in passing the ASD Persons’ Empowerment Act. Such endeavors formed the impetus for advocating for the rights of individuals with ASD in line with the Maltese law, and the setting up of the Autism Advisory Council which oversees the implementation of the National Autism Strategy. In terms of service provision, individuals in need are entitled to free health and education services on equal grounds with the rest of the child population. Parents of children with disabilities are also entitled to financial support and stipends. Arguably, inclusive education is the area in which Malta has shown remarkable advances in the disability sector through the inclusive education policy launched in 1993.^{43,44,47} Table 1 reports on prevalence, diagnostic tools, and relevant information on ASD across all three countries.

Table I Information on Prevalence Data and Diagnostic Tools Used in ASD Across the Three Countries with Approximate Estimated Autism Prevalence (per 10,000 People)

Country	Cyprus	Greece	Malta
Prevalence rates	1.8%-2%	1.2%-1.5%	1.8%-2%
Diagnostic tools	M-CHAT ADOS ICD-10 DSM-IV Clinical Observations	M-CHAT ADOS ICD-10 DSM-IV Clinical Observations	M-CHAT ADOS ICD-10 DSM-IV Clinical Observations
National Registry	In progress (2024–2028)	No	No
The existence of a National ASD Committee	Yes: Cyprus National Autism Committee-Ministry of Social Welfare	No	Yes: Autism Advisory Council
Age of Diagnosis	Around 3;6–4;0 years	Around 3;6–4;0 years	Around 18 months to 4;0 years

Discussion

The present study was set to examine the diagnosis processes and prevalence rates of ASD across Cyprus, Greece, and Malta. Furthermore, it reviewed similarities and differences documented across the variables studied. Findings revealed similarities in diagnostic tools implemented in the assessment process with clinical observations as a common denominator. Minor differences were noted in the prevalence with rates ranging between 1.5% and 2%. The figure reported aligned with global prevalence estimates. Differences in documenting prevalence rates were probably a result of methodological heterogeneity (population sampling, diagnostic tools used, geographical locations within each region, etc). Specifically, in Cyprus prevalence rates have been estimated based on data from a recent large-scale research project, whereas in Greece and Malta, prevalence rate has been extrapolated from governmental reports and clinical reports. This information is of utmost importance since establishing prevalence data permits the development of appropriate screening tools and informs evidence-based practice. On parallel grounds, prevalence data address cross-cultural and diverse geopolitical challenges.^{26,28}

As of today, information regarding the prevalence, diagnosis, and management of individuals with ASD, continues to from the “Achille’s Tendon” in ASD and continues to pose significant challenges for professionals across the globe due to geopolitical and cross-cultural diversity one encounters in documenting prevalence and coining homogeneous criteria.²³ Specifically, several challenges in establishing ASD prevalence in these areas including the presence of “gold standard” diagnostic tools and assessments are under development. The diversity of socio-economic resources is on par with the challenges for professionals and service providers emerging in each geopolitical across the globe. Rising prevalence highlights the need to increase access to services, and rehabilitation, and provide support to families of children with ASD. Furthermore, research has emphasized the inequitable support and access available to families living in low- and high-income households and the need to provide contextually relevant and responsive interventions, education and training, research, and policy.

Findings regarding ASD diagnosis, availability, and implementation of diagnostic tools in Cyprus, Greece, and Malta revealed that clinical observations specific diagnostic batteries and diagnostic manuals are systematically used (ADOS, DSM-V, ICD-10, M-CHAT). A difference that emerged from the data suggested differences in the age of diagnosis with Malta having the lowest age range at which ASD can be diagnosed. It was also noted that Cyprus is the only country with an established National Autism Committee.

ASD remains a heterogeneous disorder with its characteristics varying on a continuum of clinical characteristics and diagnostic markers. Research findings corroborate that early identification and early intervention can diminish the aberrant developmental outcome related to ASD across the individual’s daily living social, communicative, and academic well-being. A better understanding of clinical practices within and across clinicians from diverse linguist, cultural, and geographical backgrounds may support evidence-based practices that can be shared among all clinicians. The implementation of professional training programs in the effort to provide appropriate support to populations of ASD across the

lifespan forms a crucial part of the optimum management and developmental outcomes in ASD. Such issues remain of paramount importance, especially in the ASD context as they determine policy making, quality of service provision, and educational and social management of individuals with ASD. Research findings, particularly prevalence databases can inform policy-making for autism services and might support the emerging need for optimum and specialized care. There is a growing necessity for robust policies for early intervention, inclusive education, and long-term support services. Effective policy-making can also focus on disparities in ASD diagnosis and support access, as data consistently reveals that minority groups often experience delayed diagnoses and limited access to care. Policymakers can bridge this gap, and in synergy with stakeholders can improve equitable support to ensure that all individuals with autism receive timely, effective assistance across their lifespan.

The findings of the current study, although preliminary, provided a glimpse into issues about prevalence and diagnosis in three countries. Several limitations warrant further consideration. First, the reported data were drawn from diverse resources across each geographical location and with sample size and ages of reported cases bearing heterogeneity which may compromise generalizability to broader populations and countries. Future research could address these limitations by using larger and more diverse samples across many geographical locations to establish a better picture related to prevalence rates. The implementation of large-scale funded projects could enhance data accuracy and comparisons across many geographical locations. Finally, exploring the implementation and creation of related variables and mechanisms of specific assessment tools needs to consider linguistic and cultural aspects. Finally, exploring related variables and mechanisms in different contexts or populations could provide a more comprehensive understanding of the findings.

Disclosure

The authors report no conflicts of interest in this work.

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