**The global epidemiology and health burden of the autism spectrum: findings from the Global Burden of Disease Study 2021**

**Authors:**

GBD 2021 Autism Spectrum Collaborators

**Corresponding author:**

Damian Santomauro

School of Public Health, The University of Queensland

Queensland Centre for Mental Health Research, The Park Centre for Mental Health.

Locked Bag 500, Archerfield, 4108, Australia

[d.santomauro@uq.edu.au](mailto:d.santomauro@uq.edu.au)

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# Research in context

## Evidence before this study

Prior to this study, the most recent comprehensive review of the epidemiological modelling, prevalence, and health burden of the autism spectrum led by the Global Burden of Disease Collaborative Network was published on 1 August 2014 and reported on estimates from the 2010 iteration of the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD). Each subsequent iteration of GBD produced updated estimates of ASD disability, each with a series of improvements to the methods used, as well as the datasets underpinning disability estimates. We searched PubMed on the 5th June 2024 with the following search terms: (((pervasive[Title/Abstract] AND disorder\*[Title/Abstract]) OR (asperger\*[Title/Abstract])) OR (autis\*[Title/Abstract])) AND (Global[Title/Abstract] AND 2021[Title/Abstract] AND (“GBD 2021”[Title/Abstract] OR Disability[Title/Abstract] OR Prevalence[Title/Abstract] OR Burden[Title/Abstract])). This search yielded 14 studies, however, none covered GBD 2021 findings for the autism spectrum by location, age, sex, and year.

## Added value of this study

This study presents updated global estimates of the prevalence and health burden of ASD for GBD 2021 following substantial revisions to their estimation process from previous iterations of GBD. We present key methodological improvements in GBD 2021, such as exclusion of studies relying on passive case finding, new data from a systematic review update, and revisions to the estimation of disability weights. These updates contributed to substantial changes in the estimated prevalence and health burden of ASD. Globally, we estimated one in 127 individuals in 2021 were autistic with prevalence and health burden persisting across the lifespan. However, ASD was most common among children and adolescents under 20 years, where it ranked within the top ten causes of non-fatal health burden. Our analysis expands on the GBD 2021 capstone publication that presented the emerging trends in burden across all 371 diseases and injuries but did not cover in detail the epidemiology and health burden of the autism spectrum.

## Implications of all the available evidence

The revised estimation process and resulting prevalence and health burden estimates of ASD from GBD 2021 have important implications for future research, healthcare provision, and policy planning. Our estimates highlight the necessity for early detection and lifelong support services for individuals on the autism spectrum. The persistence of the health burden across the lifespan demonstrates the need for policy planning and healthcare provision that caters to autistic individuals at all stages of life. The limitations of our study, including the lack of geographical coverage of epidemiological data, point to the need for more diagnostic surveys in many parts of the world. Our study highlights the pressing need for more comprehensive research and policy initiatives that can better meet the diverse needs of the global autistic population and improve their overall quality of life.

# Abstract

**Background:** High-quality estimates of the epidemiology of the autism spectrum and the health needs of autistic persons are necessary for services planners and resource allocators. This paper presents the global prevalence and health burden of autism spectrum disorder (ASD) from the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) 2021 following improvements to the epidemiological data and burden estimation methodology.

**Methods:** Epidemiological estimates for ASD were sourced from systematic reviews. Eligible estimates were used to estimate prevalence via a Bayesian meta-regression tool (DisMod-MR 2.1). Modelled prevalence and disability weights were used to estimate health burden in years lived with disability (YLDs) as the measure of non-fatal health burden and disability-adjusted life-years (DALYs) as the measure of overall health burden. Data by ethnicity was not available. People with lived experience were involved in the design, preparation, interpretation, and writing of this manuscript.

**Findings:** An estimated 61·8 million (95% UI: 52·1–72·7) individuals (1 in every 127 persons) were on the autism spectrum globally in 2021. The global age-standardised prevalence rate was 788·3 (663·8–927·2) per 100 000 people. ASD accounted for 11·5 million (7·8–16·3) DALYs, equivalent to 147·6 (100·2–208·2) DALYs per 100 000 persons (age-standardised) and was ranked within the top ten for non-fatal health burden for youth under 20 years of age.

**Interpretation:** The high prevalence and rank for non-fatal health burden in youth underscores the importance of early detection and support to autistic youths and their caregivers globally. Moreover, persisting health burden during adulthood calls for more consideration into how our health response must evolve across the lifespan. Work to improve the precision and global representation of our findings is required, starting with better global coverage of epidemiological data so that variations across location can be better ascertained. The work presented here can guide future research efforts and importantly decisions surrounding allocation of health services that better address the unique needs of all autistic individuals.

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# Background

Autism spectrum disorder (ASD) is a developmental condition characterised by persistent difficulties in social communication and interaction, challenges related to sensory processing, repetitive behaviours, interests, or activities, and in some instances intellectual disability, all of which occur at varying levels of severity.1 Autistic persons [FOOTNOTE] are at an increased risk of social isolation, academic or employment difficulties, and may require psychosocial support into adulthood.2 Early diagnosis and intervention can improve outcomes for autistic persons, although many do not receive early support.3-6 Accurate epidemiological estimates are essential for strategic service planning and resource allocation for autistic persons and are generated as part of the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD).7

*[INSERT FOOTNOTE:* *We use identity-first language as preferred by most people with lived experience of the autism spectrum.8,9* *This approach puts any reference to the autism spectrum first within a statement. However, we do acknowledge that some people with a diagnosis of ASD prefer person-first language which emphasises the person first within a statement.]*

GBD is the largest scientific effort estimating prevalence and health burden of disorders, diseases and injuries.7 Seven iterations of the GBD reporting on the autism spectrum have been conducted, each quantifying the health burden using the disability-adjusted life-year (DALY). Each DALY represents a year of healthy life lost due to a cause. The term health burden in this manuscript refers specifically to the DALY as it is used within GBD.

The global age-standardised prevalence of the autism spectrum reported by GBD 2019 was 369.4 per 100 000 persons,10 which was relatively low compared to ASD prevalence from active case-finding methodologies (where prevalence is estimated using a diagnostic instrument in a general population survey, supplemented by a search in case registries or special education facilities).11-13 This was largely attributed to the incorporation of estimates relying on passive case finding (where prevalence is estimated using the number of pre-existing diagnoses identified through databases such as administrative or educational records). This relies on autistic persons being correctly identified through existing health care practices within the population, which have historically underestimated prevalence.14 Bias corrections for these studies were implemented, but a method to incorporate how this bias varies by geography/time was not possible given limited available data reporting the proportion of autistic persons represented using passive case-finding methodology. For GBD 2021, estimates using passive case finding were subsequently removed from the epidemiological modelling. This change, alongside new data, and revisions to the estimation of disability weights, have substantially changed the prevalence and health burden of ASD, and therefore supersede those from GBD 2019 and all previous GBD iterations. This paper summarises the revised process for estimating the prevalence and DALYs of ASD in 2021 and presents an overview of prevalence and DALYs by age, sex, and geography. This manuscript was produced as part of the GBD Collaborator Network and in accordance with the GBD Protocol.15

# Method

This study adhered to Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER, Table S1).16 A graphical overview of the process to estimate the prevalence and DALYs of ASD is presented in Figure S1. GBD 2021 followed a cause hierarchy with four levels with ASD placed at Level 3 (Appendix Section 1.2.).7 Prevalence and DALYs in GBD 2021 were estimated by sex (male and female), 25 age groups, year (1990 to 2021), and 204 countries and territories that were grouped into 21 regions and seven super-regions. For all estimates, the 95% uncertainty intervals (UIs) were calculated as the 2.5th and 97.5th percentiles of the 500 draws from the posterior distribution of each step in the estimation process. Age-standardised rates were estimated using the GBD world population age standard.17 People with lived experience were involved in the design, preparation, interpretation, and writing of this manuscript. Ethics approval and participant consent were not sought. No primary data collection was undertaken, and our dataset included non-identifiable and pre-aggerated data from existing published and/or grey literature sources.

## Search strategy

A systematic review was first conducted on 11th August 2017 to capture all available data sources on the epidemiology of ASD for GBD 2017 when ASD was first modelled as a unifying diagnosis for individuals previously meeting criteria for DSM-IV *autism* and *Asperger’s syndrome and other autism spectrum disorders* to be consistent with DSM-5.1 No start date was specified in the initial search. An update to this systematic review was conducted on 12th April 2021 as part of the GBD 2021 Study. Electronic databases PubMed, Embase, and PsycINFO were searched using a search string developed with a research librarian (Table S2). Reference lists of sourced reviews were searched for relevant studies. The Global Health Data Exchange18 (GHDx) was searched and GBD collaborators were consulted for additional sources. Both reviews adhered to Preferred Reporting Items for Systematic Reviews and Meta-Analyses19,20 (PRISMA) statement guidelines (Table S3 and Figures S2 and S3). Titles and abstracts were screened then full text studies passing the initial screening were assessed. Two reviewers checked studies for eligibility and disagreements were resolved by DS, HE, and AF.

## Inclusion criteria and data extraction

To be included, data sources needed to report the prevalence, incidence, or excess mortality of ASD in a sample representative of the general population. We followed DSM-5 and ICD-11 criteria for ASD. Estimates from older criteria (e.g., DSM-IV) were accepted, and their utility were assessed. Studies using criteria established prior to the DSM-III were excluded. No language restrictions were applied. Studies had to report enough data to estimate uncertainty surrounding estimates (e.g., confidence interval, sample size). For GBD 2021, prevalence estimates relying on passive case finding (e.g., from administrative records) known to underestimate prevalence were excluded. The extent of under-estimation in prevalence from these studies varies between locations and over time and was therefore difficult to adjust accordingly. Due to an overall lack of data on the excess-mortality, we were unable to apply the same exclusion criteria to the excess mortality data included within our analysis which continued to rely on passive case finding.

Data extracted included location, age/s, sex, number of autistic persons, sample size, uncertainty, parameter type, year/s of data collection, diagnostic instruments, criteria, and sampling methodology.

## Estimation of epidemiology

Estimates of prevalence, incidence, and excess mortality were inputs into the Bayesian meta-regression tool, DisMod-MR 2.1.21 DisMod-MR 2.1 pools heterogeneous epidemiological estimates and generates internally consistent estimates of prevalence, incidence, and excess mortality. DisMod-MR 2.1 generates estimates for locations that are missing raw data by drawing on estimates from surrounding locations. It achieves this by generating estimates across five levels: Global, super-region, region, country, and subnational locations, with prevalence from the higher level acting as priors for the lower geographical level. More detail on DisMod-MR 2.1 is described elsewhere.7,21

Two adjustments were applied to estimates prior to analysis in DisMod-MR 2.1. First, data aggregated across males and females within the study sample were split into sex-specific estimates using available data on the sex ratio of ASD (Appendix Section 1.1.). Second, known sources of bias in the input prevalence data were adjusted using network meta-regressions by Meta-Regression—Bayesian, Regularised, Trimmed (MR-BRT). More detail on MR-BRT is available elsewhere.22 Prevalence data was considered reference (optimal) if the study conducted a general population survey with additional case finding (e.g., household survey supplemented with an investigation in special education services) or population screening*.* General population surveys without additional case-finding were adjusted with a bias correction (Appendix Section 1.1). Studies reporting the prevalence of DSM-IV autistic disorder / ICD-10 childhood autism without reporting the prevalence of ASD were included with an upwards adjustment to reflect estimates of ASD (Appendix Section 1.1.).

Several prior settings informed the DisMod-MR 2.1 analysis based on the available data and feedback from experts (Appendix Section 1.2.). We allowed a time window of 15 years due to limited data across time, which meant estimates informed prevalence 15 years before and after they were collected. DisMod-MR 2.1 produced age-sex-specific prevalence and excess mortality estimates across 204 countries and territories between 1990 and 2021.

## Estimation of severity distribution

In GBD 2021, health burden was estimated across varying levels of severity by cause. The term sequala referred to mutually exclusive health states differing by levels of severity. A cause could have one or multiple sequalae each which their own corresponding disability weight. ASD contributed to the intellectual disability (ID) envelope and therefore the sequelae for ASD comprised six levels of ID: none (IQ: > 84), borderline (IQ: 70-84), mild (IQ: 50-69), moderate (IQ: 35-49), severe (IQ: 20-34), and profound ID (IQ: < 20). ID is considered as an “impairment”, for which the prevalence is modelled and treated as an “envelope”. The prevalence of all conditions that contribute to the envelope are adjusted not to exceed the total prevalence of the impairment.7

Nineteen studies using the above reference case definition and reporting the proportion of autistic persons with ID were sourced from the systematic reviews. A series of meta-analyses were conducted in R using the metafor package23,24 to estimate the proportion of autistic persons by each level of ID. Figure S4 illustrates the hierarchy of meta-analyses conducted (Appendix Section 1.3.). This process produced severity proportions to apportion prevalence estimates into sequela-specific prevalence by age, sex, year, and location (Table 1).

## Estimation of disability weights

Disability weights represent health loss due to a cause on a scale of zero (no health loss) and one (death). They were derived from surveys of the general population conducted in Bangladesh, Hungary, Indonesia, Italy, Peru, Sweden, Tanzania, the Netherlands, and the USA, and an open-access internet survey available in English, Spanish, and Mandarin.25,26 Surveys contained lay descriptions of GBD sequalae which used nonclinical language to describe each state in 35 words or less. Participants were asked to identify the ‘healthier’ option within pairs of lay descriptions. Their responses were anchored between zero and one using population health equivalence questions comparing the benefits of lifesaving and disease-prevention programmes across sequalae. The disability weights generated for ASD were across the six levels of ID (Table 1) and were calculated as a multiplicative function of the ASD disability weights, ID disability weights, and the proportion of autistic persons estimated with each level of ID (Appendix Section 1.4. and Table S4). Disability weights and severity proportions were consistently applied across age, sex, and location.

### Table 1: Severity proportions and disability weights for the autism spectrum sequelae.

|  |  |  |
| --- | --- | --- |
| **Sequela** | **Severity proportion (95% UI)** | **Disability weight (95% UI)** |
| ASD without ID | 0.446 (0.395-0.496) | 0.169 (0.114-0.236) |
| ASD with borderline ID | 0.197 (0.159-0.235) | 0.178 (0.123-0.244) |
| ASD with mild ID | 0.149 (0.110-0.191) | 0.205 (0.149-0.273) |
| ASD with moderate ID | 0.139 (0.101-0.182) | 0.252 (0.192-0.318) |
| ASD with severe ID | 0.056 (0.034-0.084) | 0.302 (0.236-0.373) |
| ASD with profound ID | 0.014 (0.006-0.026) | 0.336 (0.261-0.418) |

Note: ASD = Autism spectrum disorder. ID = Intellectual disability. UI = Uncertainty interval.

## Estimation of disability-adjusted life-years

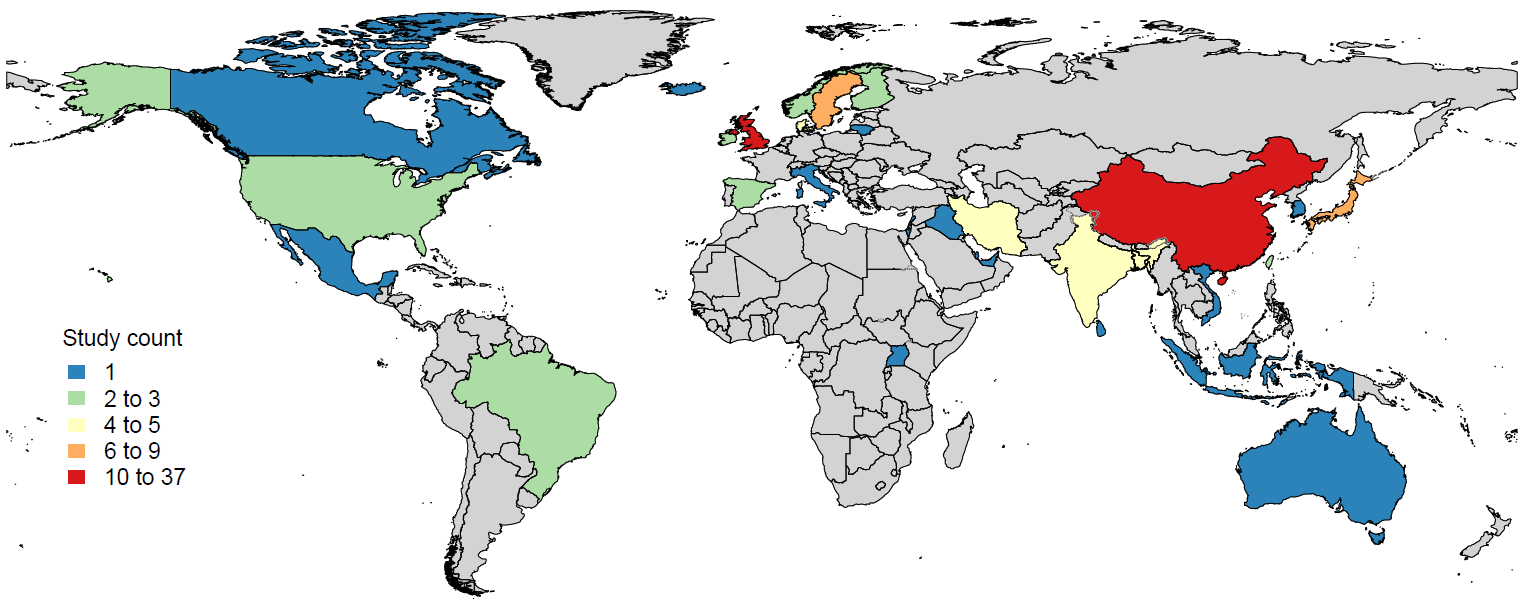
Health burden was quantified using the DALY, which is the aggregate of two health metrics: 1) Years lived with disability (YLD) capturing the disability (non-fatal burden) of a cause, and 2) Years of life lost (YLL) capturing the fatal burden of a cause.7 There were no deaths attributable to ASD as the underlying cause in GBD 2021 and therefore DALYs composed entirely of YLDs.

Sequela-specific prevalence estimates were multiplied by their respective disability weights to calculate YLDs. Since an individual may experience multiple sequelae simultaneously (i.e. more than one cause at a given time) we needed to adjust YLDs for comorbidity. The co-occurrence of sequelae was simulated within a population of 20 000 simulated individuals by age, sex, location, and year and YLDs were adjusted accordingly to ensure cumulative disability weights for any simulant did not exceed one (Appendix Section 1.5.).

# Results

DisMod-MR 2.1 was informed by 105 studies reporting 228 prevalence estimates across 33 countries and 11 of 21 regions (Figures S2 and S3 for PRISMA diagrams). Most prevalence studies focused on childhood and adolescents with only six studies reporting prevalence for adults aged 20 years or greater. There were six studies reporting 24 estimates of excess mortality across six countries within two regions. Figure 1 illustrates the number of included studies by country. Eligible studies are available via the GBD 2021 Data Input Sources Tool [https://ghdx.healthdata.org/gbd-2021/sources/].

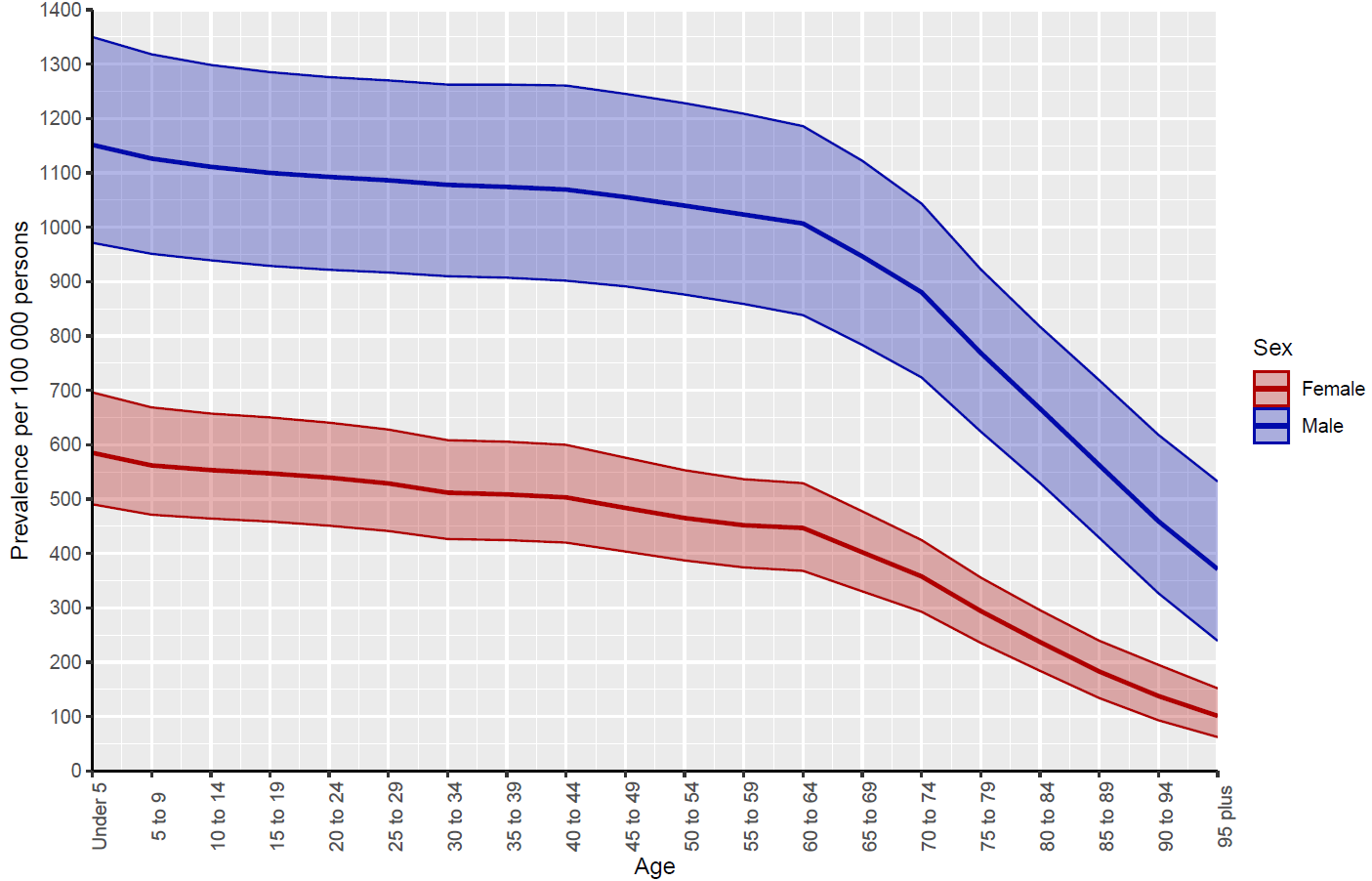
### Figure 1: Map illustrating the number of studies per country used to inform the estimation of the prevalence of ASD.



Note: Locations coloured grey did not have eligible epidemiological data on ASD. Dotted lines indicate disputed territories.

The global age-standardised prevalence of ASD in 2021 was 788·3 (95% UI: 663·8–927·2) per 100 000 people. This equates to 61·8 (52·1–72·7) million autistic persons globally. The age-standardised prevalence rate in 1990 was 773·2 (651·3–914·7) per 100 000 people. In 2021 the age-standardised rate for males was significantly higher than for females, with 1 064·7 (898·5–1 245·7) autistic males per 100 000 males compared to 508·1 (424·6–604·3) autistic females per 100 000 females. Prevalence was highest at birth and decreased with age (Figure 2). The estimated excess mortality among autistic persons was 564·8 (474·4–666·8) per 100 000 autistic males per year and 740·1 (633·4–854·9) per 100 000 autistic females per year globally (age-standardised) in 2021.

### Figure 2: Prevalence of ASD per 100 000 persons by age and sex, 2021



Note: The thick blue line represents the prevalence of ASD for males by age and the blue ribbon around this line represents its 95% uncertainty interval (UI). The thick red line represents the prevalence of ASD for females by age and the red ribbon around this line represents its 95% UI.

The highest estimated prevalence was in the High-Income super-region at 1 090·2 (95% UI: 916·3–1 279·3) autistic persons per 100 000 people. Within this super-region the highest prevalence was estimated in High-Income Asia Pacific, with 1 559·5 (1 311·3–1 832·4) autistic persons per 100 000 people, where the highest prevalence was estimated for Japan (1 586·9 [1 333·2–1 864·1] autistic persons per 100 000 people). The super-region with the lowest prevalence was Southeast Asia, East Asia, and Oceania at 669·2 (560·7–791·5) autistic persons per 100 000 people. Within this super-region the lowest prevalence was estimated in East Asia with 660·7 (549·4–785·9) autistic persons per 100 000 people, where the lowest prevalence was estimated in China (655·7 [545·1–780·4] autistic persons per 100 000 people). However, the region with the lowest prevalence was Tropical Latin America (614·5 [514·7–732·3] autistic persons per 100 000 people), and the lowest prevalence globally was estimated for Bangladesh (588·2 [486·7–696·6] autistic persons per 100 000 people) within South Asia. Prevalence by region and sex is shown in Table 2, and by country and sex in Table S5. Sequela-specific prevalence by country is shown in Table S6.

### Table 2: Age-standardised prevalence of ASD per 100 000 persons by region, super region, and globally, by sex, 2021.

| **Location** | **Both (95% UI)** | **Female (95% UI)** | **Male (95% UI)** |
| --- | --- | --- | --- |
| **Global** | 788·3 (663·8–927·2) | 508·1 (424·6–604·3) | 1 064·7 (898·5–1 245·7) |
| **Central Europe, Eastern Europe, and Central Asia** | 927·5 (778·5–1 095·3) | 644·2 (538·2–764·5) | 1 218·6 (1 021·9–1 440·2) |
| Central Asia | 886·0 (744·2–1 044·4) | 621·5 (517·0–731·8) | 1 154·4 (971·2–1 363·8) |
| Central Europe | 964·4 (810·0–1 140·6) | 662·3 (552·2–785·0) | 1 263·3 (1 058·4–1 489·7) |
| Eastern Europe | 928·5 (779·8–1 102·3) | 645·6 (535·4–773·4) | 1 226·2 (1 031·6–1 457·2) |
| **High-income** | 1 090·2 (916·3–1 279·3) | 649·8 (543·4–771·1) | 1 526·5 (1 283·2–1 786·5) |
| Australasia | 1 191·0 (993·0–1 422·7) | 709·4 (586·1–862·2) | 1 670·0 (1 387·5–2 012·1) |
| High-income Asia Pacific | 1 559·5 (1 311·3–1 832·4) | 938·8 (790·5–1 107·1) | 2 161·1 (1 815·5–2 536·3) |
| High-income North America | 1 097·2 (919·2–1 296·7) | 707·3 (589·5–838·0) | 1 486·9 (1 244·5–1 746·3) |
| Southern Latin America | 1 056·5 (885·9–1 245·4) | 662·3 (548·0–787·7) | 1 458·7 (1 216·8–1 729·8) |
| Western Europe | 896·6 (751·6–1054·5) | 477·6 (397·7–572·1) | 1 309·1 (1 099·7–1 533·1) |
| **Latin America and Caribbean** | 689·5 (579·7–820·3) | 464·9 (386·3–557·9) | 920·2 (775·0–1 087·0) |
| Andean Latin America | 684·3 (571·6–814·1) | 464·5 (385·3–555·9) | 902·4 (751·0–1 069·7) |
| Caribbean | 682·5 (572·1–813·8) | 464·7 (382·7–558·3) | 902·7 (763·6–1 069·7) |
| Central Latin America | 758·6 (639·0–897·8) | 510·3 (423·1–611·4) | 1 017·1 (855·1–1 196·5) |
| Tropical Latin America | 614·5 (514·7–732·3) | 413·4 (340·9–495·8) | 820·7 (687·6–974·5) |
| **North Africa and Middle East** | 771·8 (648·5–910·7) | 524·8 (436·1–624·1) | 1 001·3 (845·9–1 179·2) |
| **South Asia** | 686·2 (576·6–802·0) | 466·8 (389·9–557·3) | 897·0 (753·8–1 038·9) |
| **Southeast Asia, East Asia, and Oceania** | 669·2 (560·7–791·5) | 373·6 (308·4–447·9) | 950·5 (797·1–1 122·2) |
| East Asia | 660·7 (549·4–785·9) | 324·6 (267·3–391·9) | 972·2 (811·3–1 152·9) |
| Oceania | 673·2 (566·1–807·0) | 433·5 (356·8–523·6) | 898·2 (751·4–1 078·0) |
| Southeast Asia | 683·0 (574·6–809·7) | 458·6 (380·6–551·4) | 905·9 (762·1–1 069·0) |
| **Sub-Saharan Africa** | 890·2 (748·6–1 043·1) | 628·4 (526·6–743·1) | 1 164·7 (980·2–1 358·6) |
| Central Sub-Saharan Africa | 885·4 (739·7–1 046·5) | 624·5 (517·9–742·2) | 1 152·0 (963·2–1 364·4) |
| Eastern Sub-Saharan Africa | 893·5 (752·4–1045·2) | 629·0 (529·0–744·7) | 1 165·9 (980·2–1 363·2) |
| Southern Sub-Saharan Africa | 903·6 (760·1–1 069·2) | 637·3 (533·0–765·6) | 1 184·9 (995·9–1 388·5) |
| Western Sub-Saharan Africa | 886·2 (745·1–1 045·6) | 626·9 (524·2–740·0) | 1 162·9 (979·1–1 363·7) |

Note: UI = Uncertainty interval.

ASD accounted for 11·5 million (95% UI: 7·8–16·3) DALYs globally in 2021. Due to population growth, the total DALYs attributable to ASD increased from 7·9 million (5·4–11·1) DALYs globally in 1990. However, the age-standardised DALY rate remained largely unchanged between 1990 (144·5 [98·3–203·3] per 100 000 persons) and 2021 (147·6 [100·2–208·2] DALYs per 100 000 persons). In 2021 the age-standardised DALY rate varied significantly by sex, with 199·8 (136·3–282·0) DALYs per 100 000 males compared to 94·5 (64·5–133·0) DALYs per 100 000 females.

The geographical distribution in DALYs mirrored that of prevalence. At the super-region level, age-standardised DALY rates ranged between 126·5 (95% UI: 86·0–178·0) per 100 000 persons in Southeast Asia, East Asia, and Oceania to 204·1 (140·7–284·7) per 100 000 persons in the High-income super-region. At the region level, age-standardised DALY rates ranged between 114·4 (77·1–160·3) per 100 000 persons in Tropical Latin America and 293·9 (203·2–413·0) per 100 000 persons in High-income Asia Pacific. The lowest age-standardised DALY rate was estimated for Bangladesh (110·3 [75·4–154·6] per 100 000 persons) whereas the highest was estimated for Japan (299·1 [207·2–420·0] per 100 000 persons, Figure 3 for map and Table S7 for DALY rates by country and sex).

ASD was ranked 54th in DALYs in 2021 across all ages globally (0·4% [95% UI: 0·3–0·6] of total DALYs). ASD was the 44th leading cause of DALYs for males (0·5% [95% UI: 0·4–0·7] DALYs) and the 67th leading cause of DALYs for females (0·3% [95% UI: 0·2–0·4] DALYs). DALYs were highest in youth and decreased with age for both sexes (Figure 4). ASD DALYs comprised entirely of YLDs. ASD was ranked 7th leading cause of YLDs for children under 5 years (4·3% [2·7–6·5] of YLDs), 8th leading cause for children and adolescents aged 5 to 14 years (3·4% [2·1–5·1] of YLDs), and 10th leading cause for adolescents aged 15 to 19 years (2·2% [1·4–3·3] of YLDs). Across all ages ASD was ranked 21st in YLDs (1·3% [0·8–2·0] of YLDs), was the 16th leading cause of YLDs for males (2·0% [1·3–3·0] of YLDs), and the 31st leading cause of YLDs for females (0·7% [0·5–1·1] of YLDs).

### Figure 3: Map showing age-standardised DALY rates per 100,000 for ASD by quintile in 2021

A map of the world

Description automatically generated

Note: Dotted lines indicate disputed territories. DALY = disability-adjusted life-year

### Figure 4: Global DALYs attributable to ASD in 2021 by age and sex

A blue and black graph

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Note: Blue bars to the left of the vertical black line represent the estimated number of disability-adjusted life-years (DALYs; in thousands) attributable to ASD among females by age. Blue bars to the right of the vertical black line represent the estimated number of DALYs (in thousands) attributable to ASD among males.

# Discussion

This paper presents global estimates of prevalence and health burden for the autism spectrum from GBD 2021, following revision to their estimation process. In 2021, one in 127 persons globally was estimated to be autistic, substantially higher than then one in 271 estimated by GBD 2019. This difference is mainly attributed to change in GBD methodologies with the exclusion of studies relying on passive case finding (e.g., registry or administrative prevalence estimates) that likely underestimated the prevalence of the autism spectrum.14 The large increase in the estimated prevalence of the autism spectrum reflects necessary improvements in its epidemiological modelling and aligns global estimates with estimates derived from high quality epidemiological surveys.11-13

Despite the increase in prevalence of ASD in GBD 2021 compared to GBD 2019, the prevalence of ASD estimated for the US (one in 91 persons in the United States in 2021) remains more conservative than internationally cited findings from the Centers for Disease Control and Prevention indicating one in 36 children aged eight years in the United States were autistic in 2020.27 This higher prevalence was derived from a review of case notes from clinical and educational records to determine whether individuals likely met diagnostic criteria for probable ASD. As individuals were not clinically evaluated for ASD (as is done in population diagnostic surveys), this method can overestimate the prevalence of ASD.

The prevalence and DALYs attributable to ASD in GBD 2021 were higher in males than in females, with a global age-standardised sex ratio of 2.1 to 1. The removal of prevalence data relying on passive case finding resulted in a substantial decrease in the estimated sex ratio. This was consistent with a previous meta-analysis finding that studies reporting registry / administrative prevalence produced a substantially larger sex ratio than studies relying on active case finding.28 Their finding illustrated a potential sex bias for receiving diagnoses of ASD, and together with our findings, highlights the need for more consideration into how screening procedures and services can be altered to ensure that both autistic females and males receive support. There are caveats to the age-standardised global sex ratio estimated by DisMod-MR 2.1, however. Data rich regions tended to have larger sex ratios than regions with minimal or no data informing prevalence. For data-sparce locations (e.g. in sub-Saharan Africa), the sex ratio in prevalence was more conservative, contributing to a smaller sex ratio. This is an area of ongoing review as more sex-specific prevalence estimates across more geographical locations become available.

Prevalence varied substantially by region, from one in 163 persons in Tropical Latin America to one in 65 persons in High-income Asia Pacific. The high prevalence in High-income Asia Pacific was driven by high-quality data from South Korea and Japan indicating higher prevalence in this region.12,13,29,30 There are many factors contributing to the geographical variation in prevalence, including varying exposure to risk factors, cultural variation in behavioural norms, validity and choice of screening and diagnostic tools, participants’ responses to survey questions, or even their choice to participate.31,32

Prevalence did not vary substantially over time. Studies reporting an increase in the prevalence of the autism spectrum have often relied on registries or administrative records to determine prevalence. Studies using random sampling or consistent active case finding did not show this trend. This aligns with previous work suggesting autistic characteristics in the population have remained stable over time despite a rise in registered diagnoses.33 Nonetheless, the absence of temporal trends in our analysis should be interpreted with caution as we relied on a 15 year time window (reduced from 25 years) to model prevalence data. This time window may have limited our ability to explore temporal trends, but a further reduction was not possible due to data sparsity.

ASD ranked within the top ten causes of non-fatal health burden for youths under 20 years, emphasising the need for early detection and developmental support for autistic persons.3,4,34 However, most epidemiological investigations into the autism spectrum have been predominantly centred on children and adolescents, leaving a gap in our understanding of the autism spectrum in adults. The prevalence and health burden of ASD persisted across the lifespan, beginning to decline from 60 years. With most of our raw prevalence data limited to younger cohorts this age pattern was informed by excess mortality modelled by DisMod-MR 2.1 due to limited available prevalence data in adulthood. Due to limited data availability, these mortality estimates relied on passive case finding (e.g., from administrative records). This may overestimate excess mortality for all autistic persons, leading to an underestimation of prevalence in adulthood.

The service needs of autistic individuals change with age and must also consider caregivers. Caregivers can be supported by working closely with health professionals to monitor the development of their autistic child to jointly identify areas where additional support is beneficial. Early intervention facilitating learning and behavioural support for young autistic children as well as programs enhancing parental understanding are encouraged. School-age autistic children and adolescents may benefit from programmes addressing social communication difficulties, social skills training, or technology-based augmentative communication systems. Autistic adults may benefit from programs enhancing independence such as life skills and employment training but more research is required to identify the full range of effective services during adulthood. Despite their availability, many autistic persons and their care-givers residing in high-income settings cannot access services in a timely, or sustained manner and many residing in low and middle-income settings cannot access these services entirely.4,35,36 We hope that our work can contribute to the global discourse to achieve a better service response for autistic persons.

There are several limitations to our estimation process that need be considered. First, we were not able to capture all variation within the prevalence and burden of ASD across countries which were often presented within large and overlapping bounds of uncertainty. Our analyses were informed by epidemiological data from 34 countries (out of 204) across 12 (out of 21) GBD regions. Despite additional data from the review update, this reflects a small drop in the geographical coverage from the GBD 2019 Study due to the removal of estimates relying on passive case finding. Including estimates relying on passive case finding would improve geographical coverage, however, accurately quantifying the bias within these estimates remains challenging due temporal and geographical heterogeneity in autism spectrum awareness, service coverage, referral pathways, and diagnostic practices.37,38 We strongly encourage researchers and other stakeholders to initiate population-representative diagnostic surveys and active case finding methodology to investigate the prevalence of ASD; and to not rely solely on passive case finding methods which we found can underestimate the prevalence of ASD within the population. These surveys should also investigate what proportion of autistic persons are represented by passive case finding methods to help inform methods to incorporate existing data derived from passive case finding.

Second, it was difficult to quantify the amount of variation due to true differences in prevalence or due to other methodological differences between studies. We adjusted for differences in case definition and sampling methodology through bias corrections but acknowledge that these represent a small sample of the between-study variation in methodology. Studies differed in screening and diagnostic tools used, tool thresholds, and methods for accounting for nonresponse. These are avenues for future work to better respond to remaining biases within the epidemiological data.

Third, disability weights in GBD do not vary by location and are generated by survey participants’ reactions to lay descriptions of relevant health states. A separate analysis of GBD disability weights indicated they remained relatively stable across locations however this work was limited to the nine countries where disability weights surveys were conducted.25,26 Additionally, for the autism spectrum, the lay descriptions used in these surveys may be considered simplistic, incomplete, and potentially stigmatising for autistic persons.39 Many autistic persons may embrace their diagnosis as an essential part of their identity and object to the view that their diagnosis is a disability or disorder. Regardless, many autistic persons still require support and services, which are frequently delayed or unavailable.4,35 Without disability weights and subsequent DALY estimates, there is a risk of inadequate prioritisation of these essential resources for autistic persons. Previous work suggests lay persons from the general public provide the most balanced responses when evaluating lay descriptions of health states as respondents’ tend to underestimate the disability of their health states.25 Moreover, future disability weights surveys should consider generating lay descriptions and disability weights for the autism spectrum derived in consultation with autistic persons to adequately capture the disability and service needs of this population.

Fourth, the levels of severity within ASD were derived from a meta-analysis of studies capturing the proportion of autistic persons by levels of ID. This analysis only produced an overall pooled severity distribution, with insufficient data to explore variations by location, age, or sex. We expect to see variation in the severity of health loss experienced by autistic persons, for instance depending on the quality and availability of care received. New processes are under-development within the GBD framework to incorporate variations in health care access globally within disease severity. We hope to apply this to ASD in future GBD cycles.

Fifth, GBD does not yet estimate prevalence and DALYs by gender (as opposed to sex). There is emerging evidence indicating greater variation in gender diversity and sexual orientation amongst autistic persons.40 The implications of this on the service needs of autistic persons will not be reflected within our estimates and needs to be considered by service planners.

Sixth, it is important to consider the health burden experienced by autistic persons not captured in the GBD 2021 Study. GBD’s comorbidity adjustment assumes ‘independent comorbidity’ which underestimates the comorbidity between mental disorders where the comorbidity distribution changes depending on the combination of disorders experienced. Autistic individuals are often at an increased risk of experiencing a range of other mental and physical health conditions.36 For instance, a large proportion of autistic persons experience elevated rates of depressive and anxiety disorders as well as diabetes compared to non-autistic persons.41-44 Additionally, although YLLs for ASD could not be estimated via GBD methods, there is strong evidence of an elevated risk of premature mortality within autistics persons, with an increased risk of self-harm and suicide compared to the general population. In a separate analysis to GBD 2021, we explored the fatal burden attributable to the elevated risk of suicide among autistic persons. We estimated 13 400 excess suicide deaths among autistic persons globally in 2021, equivalent to 1·8% of all suicide deaths and 621 000 excess YLLs attributable to ASD.45 Collectively, the presence of comorbid conditions and elevated risk of mortality impact negatively on the health of autistic individuals, in ways which GBD 2021 burden estimates cannot yet quantify. This needs to be addressed by future research and more importantly, through increased use of prevention, early identification, and management strategies that can mitigate the impact of comorbid health conditions and reduce the risk of mortality amongst autistic persons.

## Conclusion

GBD 2021 underlined several considerations for researchers, policymakers, and communities alike as they respond to the health burden experienced by autistic persons. We estimated one in 127 individuals worldwide in 2021 was autistic, placing the autism spectrum within the top ten causes for non-fatal health burden for children and adolescents under 20 years. While the importance of early detection and intervention cannot be overstated, we must also reconsider how the service needs of autistic persons evolve across the lifespan. It is imperative to address not only the needs of autistic children and adolescents, but also of adults, who often remain under-represented in research and service provision. With epidemiological data only available for a limited number of global regions and countries, we urge researchers to initiate more inclusive population representative diagnostic surveys with active case finding to enhance geographical coverage. We hope that this study provides a foundation for future research and policy interventions, so that key stakeholders work to ensure that the unique needs of all autistic persons are met, contributing to a better, more inclusive, and understanding future.

# Author contributions

To be completed on resubmission

# Declarations of interest

To be completed on resubmission

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