Global Burden of Disease

Mental Disorders and Illicit Drug Use Expert Group



Summary of data collected and decision rules used in making regional and global estimates:

Pervasive developmental disorders

Allison Ventura, Amanda Baxter, Adele Somerville, An Pham, Roman Scheurer, Bianca Calabria, Jen McLaren, Anna Roberts, Louisa Degenhardt and Harvey Whiteford for the Mental Disorders and Illicit Drug Use Expert Group

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Working Paper

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Glossary

ARR Annualised remission rate

ASD Autistic Spectrum Disorder

CIDI Composite International Diagnostic Interview

DALY Disability-adjusted life year

DSM Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric

Association)

GBD Global Burden of Disease Project

ICD International Classification of Diseases (World Health Organisation)

LP Lifetime Prevalence

PDD Pervasive Developmental Disorders

PMP Past Month Prevalence

PYP Past Year Prevalence

WHO World Health Organisation

WMHS World Mental Health Survey

YLD Years of life lived with disability

YLL Years of life lost

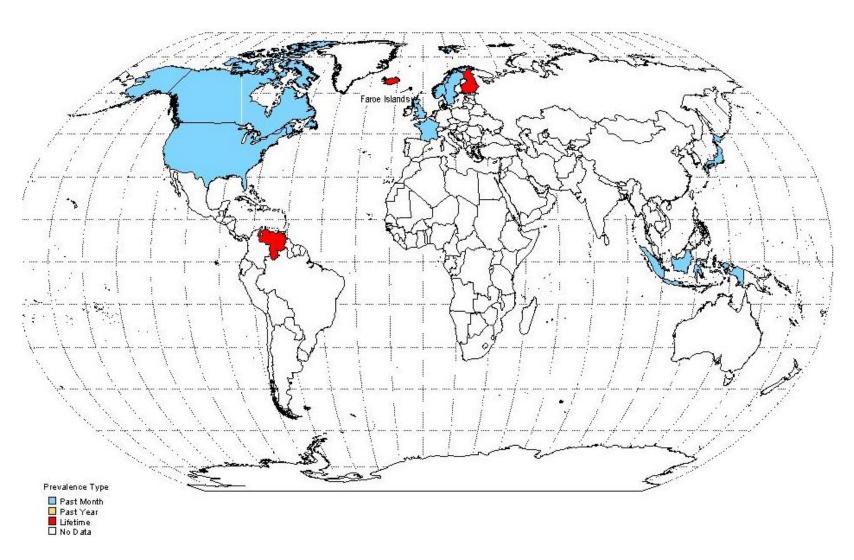
Preliminary data coverage identified for: Pervasive Developmental Disorders

□ Past Month □ Past Year ■ Lifetime □ No Data

Prevalence Type

Figure 1. Past month, past year and lifetime prevalence coverage for overall estimates of pervasive developmental disorders.

Figure 2. Past month, past year and lifetime prevalence coverage for specific diagnoses of autism or Asperger's disorder



1.0 Data summary and decision rules overview

The new Global Burden of Disease study commenced in 2007 and is the first major effort since the original 1996 GBD study to produce systematic and comprehensive estimates of the burden of diseases and injuries. It will also update the comparative estimates of the burden of risk factors. While the original 1996 GBD study produced 1990 estimates for 107 diseases and injuries and ten risk factors for eight world regions, the new study will produce 1990 and 2005 estimates for 150 diseases and injuries and more than 40 risk factors for 21 regions of the world.

Important changes will be made to the scope and nature of the estimates for mental disorders and illicit drug use. More disorders are being considered because of significant advances in epidemiological research. The original study contained estimates for unipolar depression, bipolar disorder, panic disorder, obsessive compulsive disorder, post traumatic stress disorder and illicit drug use. The new estimates will include the mental disorders covered in the original study plus eating disorders (both anorexia and bulimia), dysthymia (as well as major depression), generalised anxiety disorder, agoraphobia, social phobia, specific phobia, separation anxiety disorder, pervasive developmental disorders (autism and asperger's disorder), attention deficit hyperactivity disorder and conduct disorders.

In the 2005 update, pervasive developmental disorders are defined as any diagnosis of autism, aspergers disorder or pervasive developmental disorders not otherwise specified.

Disability-adjusted life years (DALYs) will be calculated for these health states. These will be summed to give overall burden of disease for pervasive developmental disorders.

1.1 Data sources

A systematic review was undertaken to identify sources of data containing epidemiologic parameters for pervasive developmental disorders. Papers identified in the search were sought and data containing these parameters were extracted, recorded and standardised.

Standardised approaches to literature searches, data collection, data extraction, consistency and error checking, and expert consultation and review were taken across the mental disorders. These methodologies are documented and detailed on the expert group's website: www.gbd.unsw.edu.au., but briefly can be summarised as follows:

Stages of the systematic review:

- 1. Search of peer-reviewed literature. The search strategy is consistent with the methodology recommended by the Meta-analysis of Observational Studies in Epidemiology (MOOSE) Group[1]. Three electronic databases were included in the search (Medline, Psychlnfo and Embase) with searches limited to human subjects. Search strings are available for review at http://www.gbd.unsw.edu.au/gbdweb.nsf/page/Methodology.
- **2. Identifying articles from peer-review literature that met inclusion criteria.** An extensive list of articles was picked up by the search string. From this list of several thousand articles, each was briefly reviewed for inclusion criteria:
 - Must include the specific disorder under review
 - Must present primary data
 - Must be an epidemiologic study (pharmacological treatment samples and case studies excluded)
 - Presented data for the period 1980 onward
 - When general population data at a national level were available sub-national data was excluded.
 - Samples must be representative of the general population
- **3. Obtaining full-text copies of articles.** The references of articles identified from the systematic review were compiled in Endnote. PDFs were sourced from on-line open access journals and through The Park, Centre for Mental Health, Library and the University of Queensland Library.
- **4. Data extraction.** A three level Access database was designed to accommodate the data form the mental disorders systematic search. A random sample of articles was double-checked for accuracy and consistency of data extraction and entry. In-built quality assurance was a feature of the Access database through the use of drop-down boxes and coding protocols.

A Quality Index Score was developed based on a range of variables extracted from each identified source of data so that representativeness of studies can be quantified and used for comparison. The Quality Index Score is available for review at

http://www.gbd.unsw.edu.au/gbdweb.nsf/resources/MD_Pt2_Appendicies/\$file/GBD2005+Men_tal+Disorders+Quality+Index.pdf.

In this document we present an initial summary of the prevalence data identified for pervasive developmental disorders.

We present the decision rules relating to:

- inclusion criteria for data sources.
- methodology of data extraction, and
- reporting of study characteristics and epidemiologic parameters.

Also presented here are some preliminary decision rules for:

- manipulating data,
- imputing missing data,
- pooling data within countries,
- pooling data for some parameters (for example remission and mortality), and
- our approach to production of regional prevalence estimates for mental disorders as a whole.

Further work is currently underway to identify peer-reviewed and grey literature sources that may assist with missing age-, sex- and country-specific estimates. The process of applying the rules outlined below has begun, with the first steps presented in this document.

2.0 Principles for inclusion of data sources and reporting of data.

Presented here are general rules for the inclusion of articles and data identified through the peerreview literature and through expert review. We also present the general protocol and rules for reporting of data.

2.1 Inclusion of Data Sources (including Peer-review papers)

Peer-review literature versus grey literature

A preliminary search for epidemiologic data for mental disorders identified a range of sources, including grey literature (government reports, unpublished findings, dissertations), peer-review publications and non-government organisation (NGO) data collection. Due to the wealth of data available (including data from the World Mental Health Survey) and the available time frame, the decision was taken to focus the first stage of the data search on peer-reviewed literature. Grey literature sources will be reviewed in the second stage of the project, as data sources to address the gaps in the preliminary dataset.

Justification: A large body of data is available through the peer-review literature, of sufficient quality to meet the expert group's criteria, to provide a preliminary dataset for the first round of estimates. It is anticipated that the circulation of these preliminary findings to experts in the field will yield a range of very useful suggestions for other data sources, including grey literature, to address the gaps in the data. In this way it is anticipated that maximum coverage will be achieved.

Representativeness

Where a large body of data is available for a country (e.g. for the US, Western Europe, Great Britain, New Zealand and Australia), only the nationally representative studies will be included.

Justification: Excluding excluding studies that have small samples that are likely NOT representative of the national population will be a more time-efficient process. Studies with unrepresentative samples are unlikely to be used for this GBD Project.

Diagnostic Criteria

A broad rule was adopted for all mental disorders that initial data collection for prevalence, incidence and remission estimates would be limited to data sources reporting rates based on DSM and ICD diagnostic criteria only. Papers that report use of a survey that could not demonstrate

validity against either DSM or ICD criteria were excluded. If the validity of a survey is uncertain, the opinion of an expert in the field will be sought.

Justification: Inclusion of estimates based on alternative definitions may skew the final estimates for some countries, as narrower or broader definitions would result in lower or higher estimates being reported. Further, large amounts of data are available from peer-review sources for mental disorders in many countries. Hence it was felt that additional data with estimates based on alternative definitions of the disorder would not be required as sufficient data would be available through papers in which ICD or DSM diagnostic criteria were used.

Definition of Remission

For the Global Burden of Disease project, remission from a mental disorder is defined as no longer fulfilling the diagnostic criteria for this disorder. Partial remission is therefore considered as being no longer a "case". Follow-up period for the sample must be a minimum of two years.

Remission estimates were obtained from observational studies. Studies that reported samples from randomised controlled trials or treatment other than "as usual" will be excluded as not being representative of the average case. Remission among cases of mental disorders *in treatment* (that is, treatment "as usual") will not be considered separately from out-of-treatment cases as so little data is available from community (non-treated) samples.

If several papers have been published for the same study (i.e. same cohort) at different time points, only the paper reporting the longest follow-up period will be included in the dataset.

2.2 Data Extraction and Reporting

Prevalence rate

If prevalence type was unspecified, the diagnostic tool was sought in order to determine whether prevalence was point, past month, 12-month, lifetime or another period. If the diagnostic tool was unable to be accessed or unclear, prevalence was taken as point. An exception to this rule was for samples ascertained through case registries. As these were diagnosed with the disorder AT SOME PERIOD in their lives, but possibly some time ago, prevalence was taken as lifetime. As this was most frequently the case for disorders with zero remission in studies that used birth cohorts (e.g. autism), it is assumed that this will not make a significant difference to the rate.

Cohort

Cohort size was defined in different ways according to the methods used in the studies. Typically, cohort size was defined as the sample size, specifically the number of individuals for whom useable data was collected.

However, if the sample was derived from a case register or from medical records for a geographically defined area, and:

- the degree of coverage is difficult to ascertain due to inadequate reporting, or
- coverage appears to be poor (e.g. those who seek treatment in countries where a statefunded health system is not cheaply and easily accessible), or
- coverage is reliant on an individual actively seeking treatment for a disorder which is known to have a low level of treated prevalence (e.g. depression)

then the cohort size was recorded as the number of cases identified.

Alternatively, where health checks are legislated for infants and children at regular intervals (e.g. Norway and Japan) and coverage is close to 100% (95% or higher), cohort is taken as the number of children in that age group who fall within the defined area, as we can reasonably expect that data has been obtained for that number of people.

Time period (Epoch)

- Epoch not reported

Where epoch (the year to which the estimate refers) is NOT reported within a paper, a note will be made of the fact and epoch recorded as the year two years prior to publication.

Justification: The GBD Project requires the year of the estimate in order to establish a time trend for calculation of burden. However the research team are found that it is relatively common for authors to not report details such as epoch, response rate, etc. Rather than leave a gap in the data where epoch is not reported, an overall decision was taken to estimate the epoch as two years prior to publication, on the basis that it will generally take at least two years to clean data, carry out analysis and publish results.

- Longitudinal studies

Where data collection is carried out over a period of time, the midpoint of the data collection period was taken as epoch start and midpoint of final follow-up period as epoch end. For example, if baseline data collection is 1980–1982 and final follow-up period is 2000–2004, epoch start is

recorded as 1981 and epoch end as 2002. Greater detail of different time periods is recorded as text in the comments field.

- Studies that give estimates for different time periods

Where a longitudinal study gives year-specific estimates, the <u>years that those estimates relate to</u> are recorded as epoch start and epoch end. Again, greater detail is recorded as text in the comments field. For example, if a longitudinal study reports 12-month prevalence for two samples, one ascertained 1980–1981 and the other 1990–1991, epoch is recorded as 1980–1981 for the prevalence rate specific to that particular time period and 1990–1991 for the relevant prevalence estimate.

Age Range

Where an age range is not reported in the paper, 'dummy' variables of 0 (minimum) and 99 (maximum) are inserted. If the sample is reported as 'adult' the age range was recorded as 18-99.

Remission and Mortality - Secondary Data Sources

In all cases, the primary source of data was used for all surveys for data extraction purposes. However, due to time restrictions, when a study reported data from previous years this data was included with a note that it did not come from the primary data source. Similarly, where a good quality systematic review or meta-analysis was identified, the data reported was included and clearly identified as coming from a secondary data source.

Classification of Specific diagnoses

Where an estimate is given for an ICD or DSM disorder that confers a degree of disability but is not a stand-alone GBD "Health State", the prevalence for that disorder will be included in the diagnoses-specific category that confers the most similar degree of disability.

Justification: The purpose of having several diagnoses-specific classifications under a broad disorder is so that varying levels of disability can be accounted for in YLD calculations. To exclude the prevalence of disorder subtypes will result in a lower prevalence estimate for the overall disorder and underestimation of the burden of disease.

3.0 Data sources for pervasive developmental disorders

3.1 Prevalence data

Table 1. presents the available data identified from an extensive search of the peer review literature (see www.gbd.unsw.edu.au for methodology). All data sources can be obtained from the reference list at the end of this report. The last two columns indicate whether ANY sex- and age- specific estimates were reported for that country.

Table 1. Summary of data sources available by country for prevalence of pervasive developmental disorders.

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Asia Pacific, High Income										
Brunei	-	-	-			-	-	-		
Japan	-	-	-			[2] [3] [4]		[5]	Υ	Υ
Republic of Korea (South Korea)	-	-	-			-	-	-		
Singapore	-	-	-			-	-	-		
Asia, Central										
Armenia	-	-	-			-	-	-		
Azerbaijan	-	-	-			-	-	-		
Georgia	-	-	-			-	-	-		
Kazakhstan	-	-	-			-	-	-		
Kyrgyzstan	-	-	-			-	-	-		
Mongolia	-	-	-			-	-	-		
Tajikistan	-	-	-			-	-	-		
Turkmenistan	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Uzbekistan	-	-	-			-	-	-		
Asia, East										
China	-	-	-			-	-	-		
Hong Kong	-	[6]	-	Υ	N	-	-	-		
Democratic People's Republic of Korea (North Korea)	-	-	-			-	-	-		
Taiwan	-	-	-			-	-	-		
Asia, South										
Afghanistan	-	-	-			-	-	-		
Bangladesh	-	-	-			-	-	-		
Bhutan	-	-	-			-	-	-		
India	-	-	-			-	-	-		
Nepal	-	-	-			-	-	-		
Pakistan	-	-	-			-	-	-		
Asia, Southeast										
Cambodia										
Indonesia	-	-	-			[7]	-	-	N	N
Laos People's Democratic Republic	-	-	-			-	=	-		
Malaysia	-	-	-			-	=	-		
Maldives	-	-	-			-	=	-		
Mauritius	-	-	-			-	=	-		
Mayotte	-	-	-			-	-	-		
Myanmar	-	-	-			-	-	-		
Philippines	-	-	-			-	-	-		
Reunion Island	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Seychelles	-	-	-			-	-	-		
Sri Lanka	-	-	-			-	-	-		
Thailand	-	-	-			=	-	-		
Timore Leste	-	-	-			-	-	-		
Viet Nam	-	-	-			-	-	-		
Australasia										
Australia	-	-	-			-	-	-		
New Zealand	-	-	-			-	-	-		
Caribbean										
Anguilla	-	-	-			-	-	-		
Antigua and Barbuda	-	-	-			-	-	-		
Aruba	-	-	-			-	-	-		
Bahamas	-	-	-			-	-	-		
Barbados	-	-	-			-	-	-		
Belize	-	-	-			-	-	-		
Bermuda	-	-	-			-	-	-		
British Virgin Islands	-	-	-			-	-	-		
Cayman Islands	-	-	-			-	-	-		
Cuba	-	-	-			-	-	-		
Dominica	-	-	-			-	-	-		
Dominican Republic	-	-	-			-	-	-		
French Guiana	-	-	-			-	-	-		
Grenada	-	-	-			-	-	-		
Guadaloupe	-	-	-			-	-	-		
Guyana	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Haiti	-	-	-			-	-	-		
Jamaica	-	-	-			-	-	-		
Martinique	-	-	-			-	-	-		
Montserrat	-	-	-			-	-	-		
Netherlands Antilles	-	-	-			-	-	-		
Puerto Rico	-	-	-			-	-	-		
Saint Kitts and Nevis	-	-	-			-	-	-		
St. Lucia	-	-	-			-	-	-		
St. Vincent	-	-	-			-	-	-		
Suriname	-	-	-			-	-	-		
Trinidad and Tobago	-	-	-			-	-	-		
Turks and Caicos Islands	-	-	-			-	-	-		
Europe, Central										
Albania	-	-	-			-	-	-		
Bosnia and Herzegovina	-	-	-			-	-	-		
Bulgaria	-	-	-			-	-	-		
Croatia	-	-	-			-	-	-		
Czech Republic	-	-	-			-	-	-		
Hungary	-	-	-			-	-	-		
Kosovo	-	-	-			-	-	-		
Poland	-	-	-			-	-	-		
Romania	-	-	-			-	-	-		
Serbia and Montenegro	-	-	-			-	-	-		
Slovakia	-	-	-			-	-	-		
Slovenia	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
The Former Yugoslav Republic of Macedonia	-	-	-			-	-	-		
Yugoslavia	-	-	-			=	=	-		
Europe, Eastern										
Belarus	-	-	-			-	=	-		
Estonia	-	-	-			-	=	-		
Latvia	-	-	-			-	-	-		
Lithuania	-	-	-			-	-	-		
Republic of Moldova	-	-	-			-	-	-		
Russian Federation	-	-	-			-	-	-		
Ukraine	-	-	-			-	-	-		
Europe, Western										
Andorra	-	-	-			-	-	-		
Austria	-	-	-			-	-	-		
Belgium	-	-	-			-	-	-		
Channel Islands	-	-	-			-	-	-		
Cyprus	-	-	-			-	-	-		
Denmark	-	-	-			-	-	-		
Faeroe Islands	-	-	[8]	N	Υ	-	-	[8]	N	Υ
Finland	-	-	-			-	-	[9] [10]	Υ	Υ
France	-	-	-			[11]	-	[12]	N	N
Germany	-	-	-			-	-	-		
Gibraltar	-	-	-			-	-	-		
Greece	-	-	-			-	-	-		
Greenland	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Holy See	-	-	-			-	-	-		
Iceland	-	-	-			-	-	[13]	Υ	N
Ireland	-	-	-			-	-	-		
Isle of Man	-	-	-			-	-	-		
Israel	-	-	-			-	-	-		
Italy	-	-	-			-	-	-		
Liechtenstein	-	-	-			-	-	-		
Luxembourg	-	-	-			-	-	-		
Malta	-	-	-			-	-	-		
Monaco	-	-	-			-	-	-		
Netherlands	-	-	-			-	-	-		
Norway	[14]	-	-	Υ	N	[14]	-	-	Υ	N
Portugal	-	-	[15]	N	N	-	-	-		
Saint Pierre et Miquelon	-	-	-			-	-	-		
San Marino	-	-	-			-	-	-		
Spain	-	-	-			-	-	-		
Sweden	-	-	[16] [17]	N	N	[18] [19]	-	[17] [16] [20] [21]	Y	Y
Switzerland	-	-	-			-	-	-		
United Kingdom	[22] [23] [24]	[25]	[26] [25]	Y	Υ	[22] [25]	[25]	[25]	N	N
Latin America, Andean										
Bolivia	-	-	-			-	-	-		
Ecuador	-	-	-			-	-	-		
Peru	-	-	-			-	-	-		
Latin America, Central										

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Colombia	-	-	-			-	-	-		
Costa Rica	•	-	-			-	-	-		
El Salvador	-	-	-			-	-	-		
Guatemala	-	-	-			-	-	-		
Honduras	-	-	-			-	-	-		
Mexico	-	-	-			-	-	-		
Nicaragua	-	-	-			-	-	-		
Panama	-	-	-			-	-	-		
Venezuela	-	-	[27]	Υ	N	-	-	[27]	Υ	N
Latin America, Southern										
Argentina	-	-	-			-	-	-		
Chile	-	-	-			-	-	-		
Falkland Islands (Malvinas)	-	-	-			-	-	-		
Uruguay	-	-	-			-	-	-		
Latin America, Tropical										
Brazil	-	-	-			-	-	-		
Paraguay	-	-	-			-	-	-		
North Africa/Middle East										
Algeria	-	-	-			-	-	-		
Bahrain	-	-	-			-	-	-		
Egypt	-	-	-			-	-	-		
Iran (Islamic Republic of)	-	-	-			-	-	-		
Iraq	-	-	-			-	-	-		
Jordan	-	-	-			-	-	-		
Kuwait	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Lebanon	-	-	-			-	-	-		
Libyan Arab Jamahiriya	-	-	-			-	-	-		
Morocco	-	-	-			-	-	-		
Occupied Palestinian Territory	-	-	-			-	-	-		
Oman	-	-	-			-	-	-		
Qatar	-	-	-			-	-	-		
Saudi Arabia	-	-	-			-	-	-		
Syrian Arab Republic	-	-	-			-	-	-		
Tunisia	-	-	-			-	-	-		
Turkey	-	-	-			-	-	-		
United Arab Emirates	-	-	-			-	-	-		
Western Sahara	-	-	-			-	-	-		
Yemen	-	-	-			-	-	-		
North America, High Income										
Canada	-	-	[28]	Υ	N	[29]	-	[28]	N	N
United States of America	-	-	-			[30]	-	[31] [32]	Υ	N
Oceania										
American Samoa	-	-	-			-	-	-		
Cook Islands	-	-	-			-	-	-		
Fiji	-	-	-			-	-	-		
French Polynesia	-	-	-	-			-	-	-	
Guam	-	-	-			-	-	-		
Kiribati	-	-	-			-	-	-		
Marshall Islands	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Micronesia (Federated States of)	-	-	-			-	-	-		
Nauru	-	-	-			-	-	-		
New Caledonia	-	-	-			-	-	-		
Niue	-	-	-			-	-	-		
Northern Mariana Islands	-	-	-			-	-	-		
Palau	-	-	-			-	-	-		
Papua New Guinea	-	-	-			-	-	-		
Pitcairn	-	-	-			-	-	-		
Samoa	-	-	-			-	-	-		
Solomon Islands	-	-	-			-	-	-		
Tokelau	-	-	-			-	-	-		
Tonga	-	-	-			-	-	-		
Tuvalu	-	-	-			-	-	-		
Vanuatu	-	-	-			-	-	-		
Wallis and Futuna Islands	-	-	-			-	-	-		
Sub-Saharan Africa, Central										
Angola	-	-	-			-	-	-		
Central African Republic	-	-	-			-	-	-		
Congo	-	-	-			-	-	-		
Congo (Democratic Republic of)	-	-	-			-	-	-		
Equatorial Guinea	-	-	-			-	-	-		
Gabon	-	-	-			-	-	-		
Sub-Saharan Africa, East										
Burundi	-	-	-			-	-	-		
Comoros	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Djibouti	-	-	-			-	-	-		
Eritrea	-	-	-			-	-	-		
Ethiopia	-	-	-			-	-	-		
Kenya	-	-	-			-	-	-		
Madagascar	-	-	-			-	-	-		
Malawi	-	-	-			-	-	-		
Mozambique	-	-	-			-	-	-		
Rwanda	-	-	-			-	-	-		
Somalia	-	-	-			-	-	-		
Sudan	-	-	-			-	-	-		
Tanzania (United Republic of)	-	-	-			-	-	-		
Uganda	-	-	-			-	-	-		
Zambia	-	-	-			-	-	-		
Sub-Saharan Africa, Southern										
Botswana	-	-	-			-	-	-		
Lesotho	-	-	-			-	-	-		
Namibia	-	-	-			-	-	-		
South Africa	-	-	-			-	-	-		
Swaziland	-	-	-			-	=	-		
Zimbabwe	-	-	-			-	=	-		
Sub-Saharan Africa, West										
Benin	-	-	-			-	-	-		
Burkina Faso	-	-	-			-	-	-		
Cameroon	-	-	-			-	-	-		
Cape Verde	-	-	-			-	-	-		

Region /Country	PDD Past Month Prev (PMP)	PDD Past Year Prev (PYP)	PDD Lifetime Prev (LP)	Age – specific Estimate	Sex – specific Estimate	Autism or Aspergers Past Month Prev (PMP)	Autism or Aspergers Past Year Prev (PYP)	Autism or Aspergers Lifetime Prev (LP)	Age- specific Estimate	Sex – specific Estimate
Chad	-	-	-			-	-	-		
Cote d'Ivoire	-	-	-			-	-	-		
Gambia	-	-	-			-	-	-		
Ghana	-	-	-			-	-	-		
Guinea	-	-	-			-	-	-		
Guinea-Bissau	-	-	-			-	-	-		
Liberia	-	-	-			-	-	-		
Mali	-	-	-			-	-	-		
Mauritania	-	-	-			-	-	-		
Niger	-	-	-			-	-	-		
Nigeria	-	-	-			-	-	-		
Saint Helena	-	-	-			-	-	-		
Sao Tome and Principe	-	-	-			-	-	-		
Senegal	-	-	-			-	-	-		
Sierra Leone	-	-	-			-	-	-		
Togo	-	-	-			-	-	-		

3.2 Remission data

Data pertaining to remission of pervasive developmental disorders were derived from general population cohort studies, and naturalistic longitudinal studies of outpatient samples or samples identified through case registers. Remission was defined as no longer meeting diagnostic criteria for the pervasive developmental disorder. Studies that reported a follow-up of less than two years were excluded, as were those reporting on the same cohort.

Work is continuing on sourcing and extracting data for remission of pervasive developmental disorders. Preliminary estimates and calculations will be available in January 2009.

3.3 Mortality data

Estimates of excess mortality are sought for each disorder. Where a high quality meta-analysis of excess mortality has been carried out, the derived mortality measurement will be used, with clear documentation of the source of data and authors of the study.

The data is currently being collated and estimates will be available in January 2009.

4.0 Principles for data manipulation and imputation

4.1 Prevalence estimates - data manipulation and imputation

Missing past month prevalence estimates.

Many studies report the 'lifetime' risk of mental disorders but not past month prevalence. A decision was made to apply the observed proportions, derived from studies that reported prevalence of lifetime, 12-month and past month mental disorders, to countries that only reported lifetime or 12-month cases. Where possible, and based upon studies rated as being of sufficiently high quality, region-specific proportions of past year cases among lifetime cases were applied (population-weighted if estimates were available from more than one country).

Prevalence estimates for specific diagnoses

For pervasive developmental disorders there are two "health states" (Aspergers and autism) which, for the GBD purposes, capture different levels of disability. It was found that some studies report the prevalence for the broad disorder (pervasive developmental disorder) rather than the specific diagnoses or health states required for DALY calculations. A decision was made to apply the observed proportion of prevalence for the specific diagnoses (in this case Asperger's disorder and autism) from studies that reported prevalence of both broad disorder and specific diagnoses. Where possible, and based upon studies rated as being of sufficiently high quality, region-specific rate ratios will be applied.

Missing age-specific estimates

Many studies only report an estimate for one overall age range, whereas the GBD study requires more age-specific estimates. A decision was made to apply the observed age pattern from countries that reported age-specific prevalence to countries where that data is not available. Where possible, and based upon studies rated as being of sufficiently high quality, region-specific rate ratios will be applied.

Missing sex-specific estimates

Some studies do not report a male/female specific estimate. A decision was made to apply the observed sex ratios from countries that reported male and female estimates to countries that reported only an overall prevalence estimate. Where possible and based on studies rated as being of sufficiently high quality, region-specific sex ratios will be applied (population-weighted if estimates were available from more than one country).

No direct country-specific estimates of prevalence of any sort

Further attempts will be made to source prevalence data for countries for which no data has yet been found through searching all available sources (grey literature, contacting experts, national and NGO websites). Where no direct estimates of any sort are available, the weighted region-specific estimate, derived from studies in other countries within the region, will be applied (population-weighted if estimates were available from more than one country).

No direct region-specific estimates of prevalence of any sort

Further attempts will be made to source any prevalence data for that region through all available routes (grey literature, contacting experts, national and NGO websites). Where no direct estimates of any sort are available, the region will be matched to other regions (based on population characteristics identified through sensitivity analysis), and the weighted region-specific estimate will be applied (population-weighted if estimates were available from more than one country).

Data for 1990 or 2005 are not available.

If no direct estimates are available for 1990 or 2005, but data is available for other years, attempts will be made to estimate any trend across time. If only one estimate is available and no direct estimates of trend could be made, data on trends from other countries within the same region will be used.

Multiple data sources are available for the same country and time period.

Where multiple studies have been reported for the same country in the same time period, those of low quality or not considered representative will be excluded after careful consideration, and the estimates from the remaining countries will be pooled and the median value calculated. Statistical advice will be sought on the calculation of confidence intervals around the derived median value.

Implausible estimates

Where estimates reported are thought to be implausible, based on expert opinion, possibly due to cultural differences within the survey instrument, case ascertainment or sample selection, researchers will use indirect sources to compile estimates of what the prevalence might look like if imputations are required. This can then be used as a baseline comparison for the reported estimates.

4.2 First steps of data manipulation and imputation

The first steps of data manipulation, using decision rules agreed upon by the Expert group, has begun. Any study reporting prevalence for PDD, was reviewed to determine whether multiple prevalence types (LP, PYP, PMP) were reported. Only one study [25] was identified, which reported lifetime, past year and past month prevalence of PDD. These estimates, reported by Powell and colleagues[25], were used to calculate a ratio relative to the past month prevalence:

A further search of the literature will be undertaken, as well as consultations with experts in the field, to obtain more information on likely ratios of lifetime and past year prevalence to past month prevalence.

Table 2 presents the ratios calculated for lifetime to past year to past month prevalence. The mean and median of the observed ratios are presented at the end of each list.

Table 2. Ratios of specific diagnoses for pervasive developmental disorders

Ratio of Aspergers disorder and other pervasive developmental disorders			
to autism			
Source	Person	Male	Female
Epidemiology of autistic spectrum disorders in the Faroe Islands. (Ellefsen,			
2007) [8]			
Ratio of Asperger's/atypical autism : autism	2.38 :1	2.91 : 1	1.0:1
Prevalence of PDD in seven-yr children in Sweden. (Kadesjo, 1999) [16]			
Ratio of Asperger's/atypical autism : autistic disorder	1.0 : 1		
Community survey in Venezuela. (Montiel-Nava, 2008) [27]			
Ratio of Asperger's/PDD-NOS : autism	0.55 : 1		
Community sample in boys aged 5-14 yrs in Montreal, Canada. (Fombonne,			
2006) [28]			
Ratio of Asperger's/PDD-NOS : autism	1.95 : 1		
Community survey of children aged 2-6 yrs in the United Kingdom.			
(Chakrabarti, 2001) [22]			
Ratio of Asperger's/PDD-NOS/Rett's : autistic disorder	2.71:1		
Mean	1.72 : 1	2.91 : 1	1.0:1
Median	1.95 : 1	2.91 : 1	1.0:1

Further investigations will be carried out to determine if region-specific ratios can be calculated. The median of these ratios will be used to impute data from surveys that only report on past year or lifetime prevalence of pervasive developmental disorders. Median rather than mean will be used to minimise the influence of extreme ratios. Sex specific ratios will be used for studies that report prevalence of PDD disaggregated by sex.

4.3 Remission estimates - data manipulation and imputation

Remission rates

Where several remission data sources are available across different follow-up periods, the annualised remission rates (ARR) will be calculated and pooled as per methodology described by Mathers and colleagues [1] and Saha and colleagues [33].

ARR weighted (%)

$$d = \sum [a^{(-\ln(1 - b))/c}]/\sum a$$

The pooled annualised remission rate will be used across all countries. While it is acknowledged that remission may differ in countries where treated prevalence differs, insufficient data (country-specific treated prevalence and difference in remission rate by country) are available to estimate country- or region-specific remission rates.

4.4 Mortality estimates - data manipulation and imputation

Mortality rates

The derived estimate for excess mortality will be used across all countries. While it is acknowledged that mortality may differ in countries where treated prevalence differs, insufficient data (country-specific treated prevalence and country-specific excess mortality estimates) are available to estimate country- or region-specific remission rates.

Reference List

- 1. Stroup, D.F., Berlin, J.A., Morton, S.C., Olkin, I., Williamson, G.D., Rennie, D., et al., *Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis of Observational Studies in Epidemiology (MOOSE) group.* . JAMA, 2000. **283**(15): p. 2008-12.
- 2. Honda, H., Shimizn, Y., Imai, M., and Nitto, Y., *Cumulative incidence of childhood autism: a total population study of better accuracy and precision*. Developmental Medicine & Child Neurology., 2005. **47**(1): p. 10-18.
- 3. Sugiyama, T. and Abe, T., *The prevalence of autism in Nagoya, Japan: A total population study.* Journal of Autism and Developmental Disorders. , 1989. **19**(1): p. 87-96.
- 4. Honda, W., Shimizu, Y., Misumi, K., Nimi, M., and Ohashi, Y., *Cumulative incidence and prevalence of childhood autism in children in Japan.* British Journal of Psychiatry., 1996. **169**: p. 228-235.
- 5. Tanoue, Y., Oda, S., Asano, F., and Kawashima, K., *Epidemiology of infantile autism in southern Ibaraki, Japan: Differences in prevalence in birth cohorts.* Journal of Autism and Developmental Disorders. Vol 18(2), Jun 1988, pp. 155-166, 1988.
- 6. Wong, V.C.N. and Hui, S.L.H., *Epidemiological study of autism spectrum disorder in China.* Journal of Child Neurology. , 2008. **23**(1): p. 67-72.
- 7. Wignyosumarto, S., Mukhlas, M., and Shirataki, S., *Epidemiological and clinical study of autistic children in Yogyakarta, Indonesia.* Kobe Journal of Medical Sciences, 1992. **38**: p. 1-19.
- 8. Ellefsen, A., Kampmann, H., Billstedt, E., Gillberg, I.C., and Gillberg, C., *Autism in the Faroe Islands. An epidemiological study.* Journal of Autism and Developmental Disorders., 2007. **37**(3): p. 437-444.
- 9. Mattila, M.-L., Kielinen, M., Jussila, K., Linna, S.-L., Bloigu, R., Ebeling, H., et al., *An epidemiological and diagnostic study of Asperger Syndrome according to four sets of diagnostic criteria*. Journal of the American Academy of Child & Adolescent Psychiatry., 2007. **46**(5): p. 636-646.
- 10. Kielinen, M., *Autism in Northern Finland*, in *Department of Pediatrics*. 2005, Univeristy of Oulu: Oulu.
- 11. Fombonne, E., Du Mazaubrun, C., Cans, C., and Grandjean, H.I.n., *Autism and associated medical disorders in a French epidemiological survey.* J Am Acad Child Adolesc Psychiatry. , 1997. **36**(11): p. 1561-1569.
- 12. Fombonne, E. and Du Mazaubrun, C., *Prevalence of infantile autism in four French regions.* Social Psychiatry and Psychiatric Epidemiology, 1992. **27**(4): p. 203-210.
- 13. Magnusson, P. and Saemundsen, E., *Prevalence of autism in Iceland.* Journal of Autism and Developmental Disorders. , 2001. **31**(2): p. 153-163.
- 14. Sponheim, E. and Skjeldal, O., *Autism and related disorders: Epidemiological findings in a Norwegian study using ICD-10 diagnostic criteria.* Journal of Autism and Developmental Disorders., 1998. **28**(3): p. 217-227.
- 15. Oliveira, G., AtaÃde, A.Ã.o., Marques, C., Miguel, T.S., Coutinho, A.M., Mota-Vieira, L., et al., *Epidemiology of autism spectrum disorder in Portugal: Prevalence, clinical characterization, and medical conditions.* Developmental Medicine & Child Neurology., 2007. **49**(10): p. 726-733.
- 16. Kadesjo, B., Gillberg, C., Hagberg, B., Gillberg, C., and Hagberg, B., *Autism and Asperger syndrome in seven-year-old children: A total population study.* Journal of Autism and Developmental Disorders., 1999. **29**(4): p. 327-331.
- 17. Gillberg, C., Cederlund, M., Lamberg, K., and Zeijlon, L., *Brief Report: "The Autism Epidemic". The Registered Prevalence of Autism in a Swedish Urban Area.* Journal of Autism and Developmental Disorders., 2006. **36**(3): p. 429-435.

- 18. Arvidsson, T., Danielsson, B., Forsberg, P., Gillberg, C., Johansson, M., and Kjellgren, G., *Autism in 3-6-year-old children in a suburb of Goteborg, Sweden.* Autism., 1997. **1**(2): p. 163-173.
- 19. Ehlers, S. and Gillberg, C., *The epidemiology of Asperger syndrome: A total population study.* Journal of Child Psychology and Psychiatry. Vol 34(8), Nov 1993, pp. 1327-1350, 1993.
- 20. Gillberg, C., Steffenburg, S., and Schaumann, H., *Is autism more common now than ten years ago?* British Journal of Psychiatry., 1991. **158**(mar): p. 403-409.
- 21. Steffenburg, S. and Gillberg, C., *Autism and autistic-like conditions in Swedish rural and urban areas: A population study.* British Journal of Psychiatry. , 1986. **149**(july): p. 81-87.
- 22. Chakrabarti, S. and Fombonne, E., *Pervasive developmental disorders in preschool children.* JAMA: Journal of the American Medical Association. , 2001. **285**(24): p. 3093-3099.
- 23. Green, H., McGinnty, A., Meltzer, H., Ford, T., and Goodman, R., *Mental Health of Children and Young People in Great Britain, 2004.* UK National Statistics, 2004: p. 1-156.
- 24. Ford, T., Goodman, R., and Meltzer, H., *The British child and adolescent mental health survey 1999: The prevalence of DSM-IV disorders.* Journal of the American Academy of Child and Adolescent Psychiatry, 2003. **42**(10): p. 1203-1211.
- 25. Powell, J.E., Edwards, A., Edwards, M., Pandit, B.S., Sungum-Paliwal, S.R., and Whitehouse, W., Changes in the incidence of childhood autism and other autistic spectrum disorders in preschool children from two areas of the West Midlands, UK. Developmental Medicine & Child Neurology., 2000. **42**(9): p. 624-628.
- 26. Scott, F.J., Baron-Cohen, S., Bolton, P., and Brayne, C., *Brief report: Prevalence of autism spectrum conditions in children aged 5-11 years in Cambridgeshire, UK.* Autism., 2002. **6**(3): p. 231-237.
- 27. Montiel-Nava, C. and Pena, J.A., *Epidemiological findings of pervasive developmental disorders in a Venezuelan study.* Autism, 2008. **12**(2): p. 191-202.
- 28. Fombonne, E., Zakarian, R., Bennett, A., Meng, L., and McLean-Heywood, D., *Pervasive Developmental Disorders in Montreal, Quebec, Canada: Prevalence and Links With Immunizations.* Pediatrics, 2006. **118**(1): p. e139-150.
- 29. Bryson, S.E., Clark, B.S., and Smith, I.M., First report of a Canadian epidemiological study of autistic syndromes. Journal of Child Psychology and Psychiatry., 1988. **29**(4): p. 433-445.
- 30. Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., and Murphy, C., *Prevalence of autism in a US metropolitan area.* JAMA: Journal of the American Medical Association., 2003. **289**(1): p. 49-55.
- 31. Croen, L.A., Grether, J.K., Hoogstrate, J., and Selvin, S., *The changing prevalence of autism in California*. Journal of Autism and Developmental Disorders., 2002. **32**(3): p. 207-215.
- 32. Ritvo, E.R., Freeman, B.J., Pingree, C., Mason-Brothers, A., and et al., *The UCLA-University of Utah epidemiologic survey of autism: Prevalence.* American Journal of Psychiatry., 1989. **146**(2): p. 194-199.
- 33. Saha, S., Barendregt, J.J., Vos, T., Whiteford, H., and McGrath, J., *Modelling disease frequency measures in schizophrenia epidemiology.* Schizophrenia Research, 2008. **104**(1-3): p. 246-254.

Appendix

Flowchart of systematic data search for Mental Disorders

