



AUTISM IN PINK: Prevalence Study of Females with Autism in the Four Participating Countries

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Date	17 December 2013



This project has been funded with the support of the Lifelong Learning Programme of the European Union. This publication reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained herein



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Prevalence study of females with autism in the four participating countries

Prevalence figures

From the data that have been researched the most recent and robust reported rates of autism in the four countries of the Autism in Pink (AiP) project are as follows:

Country	Population	Prevalence of ASD overall	M/F ratio from data	Comment
UK	62,041,000	98-116 per 10,000 approx 1.1%	3.3-1 M/F	Prevalence studies of children and adults Similar M/F ratio reported for adults
Spain	46, 951,000	12.97 per 10,000 approx 0.13%	2-1 M/F	Prevalence study of school-age children
Portugal	10,600,000	9.2 mainland 15.6 Azores per 10,000 average approx 0.12%	5-1 M/F	Prevalence study of school-age children
Lithuania	3,200,000	17.1 per 10.000 approx 0.17%	1.9- 1 M/F	Prevalence study of school-age children

Commentary on Data

Some form of autism is said to affect 1% of the world's population. In less well-developed countries, or where services are limited or not available this can result in children or adults with the condition facing extreme hardship and even a struggle for survival. Poverty, abuse and neglect worsen the impact of the condition, making the early detection of cases important. Calculating prevalence therefore is often the first step toward launching government and non-profit mental health services in various countries that can provide more appropriate responses for these children. Numbers can also lead to scientific insights on the genetic, environmental and cultural underpinnings of autism.

A recurring question is whether there are differences between countries, and if there are, whether these relate to real differences or diagnostic artefact. This also relates to an examination of stereotyped beliefs about autism that go to the heart of this project – namely the under-recognition of autism in females.

Only in the UK has a study been made of adults. This is the population most likely to inform on the prevalence of females. Otherwise prevalence data do not include those diagnosed in adulthood. There has been no large-scale definitive study of females with autism and no studies of the prevalence of autism in female adults.

Spanish studies (Aguilera et al 2007), the data distribution of the different diagnostic categories found in Seville is quite similar to the earlier Spanish data obtained by Belinchón (2001). These data do not show marked differences between male and female except in Asperger syndrome where the rate is 3-1 M/F.

UK studies comprised a large cohort of school-age children in the south east of England (Baird et al 2006) and a study of adults in the north of England (Brugha et al 2001).

The Portuguese study (Oliviera et al 2007) was a large study of the mainland and Azores.

The AiP Portuguese partner is collecting data on prevalence that will be available in September, but it is not known how systematic this study will be. It is unlikely to meet the established epidemiological criteria for such studies that need to be rigorous and controlled but could be a helpful 'snapshot'.

The Lithuanian study (Lesinskiene 2000) reports on a school age cohort in Vilnius and was reported in the Pomona EU report of 2011.

Prevalence rates may be an artefact of the public policy toward diagnosis and type and availability of diagnostic centres, the underlying philosophy and training of clinicians and the instruments used to diagnose autism. Also the lower rates of autism in females are related to a consequence of lower awareness of female autism and the atypical clinical presentation that often occurs in such cases.

The first prevalence studies in any region of the world typically find low numbers. For instance, in new initial studies from around the world, Brazil found 27.2 cases of autism per 10,000 people, a 2012 report from Oman found 1.4, compared with the oft-quoted U.S. average of 66 or UK rate of 116. Similarly small numbers have come out of studies in China (16.1), Indonesia (11.7) and Israel (10) (Kim et al 2011).

These low rates are most likely to be the result of the methods used. Most first-pass epidemiological studies are based on a review of medical records, which are often incomplete or non-existent, depending on the state of a country's level of awareness of autism, healthcare system and the number of clinics with experts qualified to diagnose childhood disorders. This 'records based system' means that only those cases known about will be counted. In particular, minority groups and females particularly are likely to be overlooked as they may not meet basic established criteria for detection. There are also differences between 'clinical' and general populations.

Even where there have been repeated studies of prevalence there are difficulties in determining true prevalence. The U.S. data collected by the 'Centers for Disease Control and Prevention' shows the [highest autism prevalence](#) in states with the best autism health and support services, such as Arizona (121 cases per 10,000 people), Missouri (121) and New Jersey (106). In contrast, areas with fewer services have lower rates, such as Alabama (60), Arkansas (69) and Florida (42). There are also more robust detection rates in educational as opposed to health based services. This is probably where the differences and difficulties of the children are more obvious because they occur within the social context of other children, rather than a clinical setting. Although not directly related to the European context it is likely

that similar factors will apply although the premise that services cause autism is clearly nonsense as these children will still exist whatever the label used to describe them.

Over time as more parents and clinicians and other professionals become familiar with autism, the prevalence rate goes up. We are now beginning to see this in minority groups and also women and girls, where there is a growing clinical interest. In many parts of the world, including the U.S., U.K., Canada, Japan and Scandinavia, the rates of autism were flat through the late 1980s, and then apparently out of the blue a massive rise happened at the same time (Fombonne et al 2011). The rise is probably not due to any form of mysterious global environmental exposure and certainly not the MMR vaccine - but more likely to reflect new concepts of autism worldwide. Included in this growing awareness is the concept of female autism.

There is now consensus that methodological and cultural factors explain the bulk of differences in autism prevalence around the world (Zaroff and Uhm, 2012). One of the benefits of systematic prevalence studies is our ability to uncover or discount various contributory societal and medical factors. There is also the possibility of genetic differences among populations, especially in those parts of the world where there is population stability. For example, U.S. prevalence studies show that autism rates in Hispanic communities are lower than in non-Hispanic communities, even when adjusted for socioeconomic factors. In contrast, the highest recorded autism prevalence is from a 2008 study in Japan, which calculated 181 cases per 10,000 people. One untested but provocative theory is that in Hispanic cultures, where gregariousness is highly valued, the features of autism could affect one's reproductive opportunities more than in Asian cultures, which value solitude and seriousness, especially in men. But no robust data exists for males versus females, perhaps due to selection bias and inherent flaws in detection and diagnostic processes.

Low autism prevalence is not confined to poor countries. A handful of small studies in France, for example, have found rates around 5 cases per 10,000 people. One study in Germany calculated it to be 1.9, and another in Portugal, 16.7.

Differences in scientific approach among these countries may affect the results. [Elsabbagh et al \(2012\)](#) in a systematic review comment "in some European countries, they have very psychodynamic views about autism, if you don't think this disorder is driven by biological causes, then you wouldn't think there was any use in doing epidemiological studies or trying to understand causal pathways." However, modern psychodynamic models do not discount the contribution of social and biological factors in individual development and it is unlikely that forms of ASD are not entirely of biological origin.

Females with social and communication disorders may be much more likely to attract alternative diagnoses. Eating disorders such as Anorexia Nervosa, Social Anxiety Disorder, schizophrenia and Personality Disorder are all diagnostic labels that women with autism are likely to attract in the absence of gender-sensitive diagnostic protocol; hence investigation of these populations is likely to be informative.

Commentary on absence of data

There is a dearth of prevalence information derived from systematic studies or at government level that covers females with ASD. Even general data is variable. Systematic prevalence studies from the UK suggest that the prevalence rate for all ASD is around 1.1 % (NAS 2013). As previously discussed, these variations could be explained by the availability of academic research resources, awareness levels, age of the children screened, the diagnostic criteria

used, stability of diagnosis and the country studied. Numerous other factors related to whether urban or rural and the availability of clinical services is known to be important in influencing reported prevalence rates.

The wide disparity between countries and the lack of robust data has long been a topic of interest to the EU (and elsewhere) and has led to earlier initiatives. In February 2005, the European Commission for Health and Consumer Protection Directorate-General stated the following conclusions on ASD:

- The EU lacks good data to test hypotheses on secular changes in the incidence of autism. Because of specific methodological limitations, the high prevalence rates reported in recent autism surveys in the EU and in the USA cannot be used to derive absolute conclusions on this issue.
- An ASD response policy is necessary in the EU.
- More complex monitoring systems than those currently in place are needed to address the issue of changes in the prevalence of ASD.

In 2004, the European Commission, by way of oral answer to Kathy Sinnott MEP (Ireland) stated that there was ***'no comprehensive or comparable data at EU level concerning the incidence or prevalence of this disease'*** and further stated that it would welcome project proposals in the area of autism.

In response, a network of professionals and stakeholders concerned with ASD, the European Autism Alliance (EAA) drew up the **European Autism Information System Project (EAIS)** supported by EU funding. The EAIS Project proposal included several aims related to understanding the population of people affected with an ASD in the EU.

The central aims of this first phase of the *"Strategy for the Development of an ASD Prevalence Estimate within the framework of the EAIS project"* were to:

- Improve the knowledge of characteristics of the ASD services related to public health, the educational system, social services and/or parents' organisations existing in those countries where the EAIS project is being carried out and to find the pathway that people with ASD need to follow to access these services.
- Obtain information about the potential difficulties accessing data in ASD prevalence studies when these studies are developed in European countries.

This project reported in 2010 but as far as can be ascertained was unable to reach a conclusion on prevalence and the gender ratios were not part of its remit. Consequently there are still no reliable data on prevalence in the EU.

The general situation regarding females in participating countries

The situation regarding females starts with diagnosis. In all partner countries, diagnostic tools and tests appear in the main to have been based on males, simply because there have traditionally been more males to base them on, and it was not recognised that the clinical presentation in females with autism can be very different.

It is gradually being realised now in some countries across the world including the UK, Scandinavia, USA and Australia, that different parameters are needed and different and more gender specific questions must be asked during the process of carrying out diagnostic tests,

in order to be able to identify autism in some females. At present these do not exist in an agreed format.

In the UK, Dr Judith Gould (Consultant Clinical Psychologist and Director at the NAS Lorna Wing Centre for Autism) is working on understanding why females with autism are under-diagnosed. She is developing female-specific diagnostic tests and training, and feels that in the UK the more subtle manifestations of autism in women are beginning to be identified. But this is only very recent; people in the health and educational professions are not automatically being given training on females and autism, so it is thought that many girls and women with autism are still be missed in the UK and that this is happening even more in the other participating countries.

None of the participating countries have services specific to females with autism; females are simply counted among the general autism population. It has not been taken into account that because of the apparent higher prevalence of males with autism in all countries, support and strategies tend to be based on observation and research where males are more often the subjects.

There are thought to be few schools or residential establishments specific to females with autism, and very few individual educational and social work professionals in any of the countries that recognise that the differences between the needs and characteristics of autistic males and females. Consequently, females are frequently overlooked or considered ineligible for support through the educational and social service systems because they appear not to have marked difficulties in coping with life. As such difficulties are frequently masked by superficially good coping skills but on closer examination it becomes clear that they experience huge stress and exhaustion as a result of trying to make sense of and survive in the social world.

In the UK, a senior autism education professional Dr Jacqui Ashton-Smith has been key in trying to address the specific needs of females with autism in education; her ideas are becoming better known, but have yet to be incorporated into to most literature and attitudes regarding supporting people with autism.

In the UK, there are some informal support groups that are for women or girls only, but these are few and far between and the content is unknown. There is already difficulty around funding general support groups; this is exacerbated by trying to make them specific to females even though they do seem to benefit more from being in groups where males are not included.

The realisation that some women with autism present a very much subtler manifestation of autism has led to conferences specifically about women and girls on the autism spectrum in the UK over the last few years.

Awareness of the situation regarding females with autism is beginning to grow, but in the general public it is still seen as a predominantly male condition. The diagnosis of the singer Susan Boyle with Asperger syndrome has had a huge impact on public interest in the UK but as to whether this will be sustained it is unknown. Also, awareness of autism in women is more advanced in the Scandinavian countries but not other parts of Europe. In the other partner countries, conferences about females on the autism spectrum are not yet taking place, so awareness specifically of women and autism is lower.

Recommendations

A pan-European systematic study of prevalence of females would allow better recognition of this group and prevent inappropriate diagnosis and treatment responses. Such a study should include adults as well as children and should recognise the different presenting characteristics of females. Diagnostic process should allow for this clinical variation and pay attention to early developmental history as well as presenting symptoms, which are less reliable indicators of underlying ASD.

The EU-funded EAIS seems to have been discontinued but such a resource if resurrected could be used to obtain such data. Failing this a pan-EU prevalence study to ascertain the prevalence of females should be commissioned. The group comprised Bo"lte or Elsabbagh should also be considered for this work.

The Pomona datasets may also offer an opportunity to build on existing work, noting the revisions that are pending to the diagnostic categorisation of ASD planned in ICD 11.

EU conferences to increase awareness of the females and autism specifically would also be highly recommended so that EU countries can begin to understand more about the predicament of females with autism, and work on improving diagnosis and support systems.

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