J Autism Dev Disord
DOI 10.1007/s10803-011-1391-x

ORIGINAL PAPER

The Prevalence of Autism Spectrum Disorders in Toddlers: A Population Study of 2-Year-Old Swedish Children

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Abstract Autism Spectrum Disorder (ASD) is more common than previously believed. ASD is increasingly diagnosed at very young ages. We report estimated ASD prevalence rates from a population study of 2-year-old children conducted in 2010 in Gothenburg, Sweden. Screening for ASD had been introduced at all child health centers at child age 21/2 years. All children with suspected ASD were referred for evaluation to one center, serving the whole city of Gothenburg. The prevalence for all 2-year-olds referred in 2010 and diagnosed with ASD was 0.80%. Corresponding rates for 2-year-olds referred to the center in 2000 and 2005 (when no population screening occurred) were 0.18 and 0.04%. Results suggest that early screening contributes to a large increase in diagnosed ASD cases.

Keywords Autism · Autism spectrum disorder · Prevalence · Early detection · Screening · Diagnostic instruments

Introduction

Autism spectrum disorders (ASDs) are severely disabling neurodevelopmental conditions with a complex heterogeneous biological etiology (Coleman and Gillberg 2011). Prevalence surveys of ASDs have been carried out in many countries during the last decades. Methodological differences in case definition and case finding make comparison difficult. Different populations have been studied at different times. The prevalence rates have gone dramatically up over time, from about 4 in 10,000 children (Gillberg 1984; Lotter 1966; Wing et al. 1976) to recent estimates for ASD in Europe and the US around 0.6–1% of all school-age children (Baird et al. 2006; Fombonne 2009; Gillberg et al. 2006). The increase has been considered to most likely represent changes in the definitions, widening of diagnostic criteria and awareness both among professionals and the general public, although an actual increase in prevalence might be possible. It is of considerable interest that Gillberg reported a minimum rate of ASD of 0.69% in a cohort screened in the 1970s, although, at the time, the disorders were referred to as "psychotic behavior" (Gillberg 1983).

In all published studies boys have been reported to be much more often affected by ASDs than girls, in a ratio of about 2:1 to 6.5:1. The male to female ratio is usually reported to be even higher for ASDs in the normal IQ range, such as in the case of Asperger syndrome (Johnson and Myers 2007).

Children with ASDs are currently diagnosed more frequently at younger ages. Most studies of ASD prevalence have referred to schoolchildren. There have only been a few studies of ASD prevalence in children under age 7 years. In Sweden, Kadesjo et al. (1999), in a population study of children aged 6–7 years, found a prevalence of ASDs of 1.2%. A study from South-Carolina (Nicholas et al. 2009) presented a prevalence of ASDs among 4 year-olds of 0.8% with a male to female ratio of 4.7:1 in a population of 8,156 4 year-old. In a recent report from the UK Baron-Cohen et al. (2009) found an estimated prevalence of 1.6% when different methods had been used to estimate prevalence rates of ASD among children 5–9 years of age. A study from

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Published online: 03 November 2011

Stockholm, Sweden, by Fernell and Gillberg (2010) reported an ASD prevalence rate of 0.6% in children 6 years and under.

The diagnosis of ASD is relatively stable over time (Eaves and Ho 2004; Gillberg 1990; Lord 1995; Lord et al. 2006). In a recent prospective study (n = 89) the stability of the ASD diagnosis was 100% when toddlers were assessed at 21.5 months and reassessed at 46.9 months, although some changes in severity of symptoms in the autism spectrum was found (Chawarska et al. 2009).

In the following we describe the estimated prevalence rate of ASD in 2-year-old children based on results from a population study performed in 2010 in Gothenburg, Sweden. Several epidemiological studies have been conducted earlier by our group in Gothenburg. Already in the 1,980s a rise in the prevalence of autistic disorder and autistic-like conditions in children was reported. The estimated prevalence was 4.0/10,000 in 1980, 7.5/10,000 in 1984 and 11.6/10,000 in 1988 in Gothenburg. Even though the estimated prevalence rates referred to partly different age cohorts, it was already at that time concluded that the apparent increase was is in part due to better awareness and detection. It was also suggested that some of the increase of prevalence during the 1980s could be attributed to children born to immigrant parents (Gillberg 1984; Gillberg et al. 1990, 1991). In these earlier studies typical cases of autistic disorder accounted for 75% of cases. Only 20% had normal or near-normal IQs. Gillberg also described early symptoms in autism from the first years and the stability of the diagnosis of ASD made before the age of three (Gillberg et al. 1990).

Symptoms of autism are usually noticed from the first years. Despite the increasing knowledge obtained through earlier studies from our own city and across the world, it had been obvious for many years that, children were relatively rarely referred to the clinic and diagnosed with ASD under the age of 4 years. There was, as had been reported from many studies (De Giacomo and Fombonne 1998; Siegel et al. 1988) a considerable delay from the first symptoms of autism and from first parental concern to diagnosis. Most of the children were near or well into school age when the diagnosis was made. There was, at the same time, growing evidence of the efficacy of early intervention for children with autism which had lead to the emphasis of early diagnosis and the need for standardized screening for autism in addition to ongoing developmental surveillance (American Academy of Pediatrics 2006). In 2005 it appeared in Gothenburg, that the level of diagnosed ASD in children <3 years had decreased to an extremely low level and this prompted the planning of new and improved screening and diagnostic measures. Against this background a project for early detection, clinical diagnosis and intervention in autism was started in Gothenburg. The planning of the project started in 2006. From 2008 the education and training courses for the medical staff at the child health centers (CHCs) started and from 2009 screening started at some CHCs in the city.

In the present report we estimate the prevalence rates for ASD in 2-year-olds on the basis of a total population study in Gothenburg in 2010. Estimated population prevalence rates for clinically diagnosed ASD in the same age group from 2000 and 2005 were also estimated for comparison.

Methods

A clinical and research collaboration project aimed at early detection, diagnosis and early interventions for ASD in toddlers across Child Health Centers (CHCs), the Child Neuropsychiatry Clinic (CNC) and the local habilitation service, is ongoing in Gothenburg. The CHCs are responsible for developmental monitoring of toddlers, the CNC is a specialized diagnostic clinic, and the habilitation services are responsible for delivering adequate interventions for the children with autism. Gothenburg is a city on the Swedish west-coast with a total population of 513,751 at the end of 2010. An ASD screening procedure was introduced in 2009 at all CHCs (under the supervision of the Chief Medical officer of the CHC authority) as were strict routines for further referral to the CNC for evaluation and clinical diagnostics in cases raising suspicion of ASD. Services for early intervention would be made available without delay to all children with an ASD diagnosis.

Study Population 2010

The study population consisted of all 2-year-olds, born in 2007 or 2008 (and living in the city of Gothenburg in 2010), referred from the CHCs to the CNC, at the age of 2 years (≥24 months and <36 months), with a suspicion of ASD during 2010 and diagnosed there with an ASD. The CNC serves the whole city with neuropsychiatric diagnostic work–up in young children. Most children under 5 years of age where ASD or another major neuropsychiatric disorder is suspected are referred to the CNC from the CHCs, but children might also be referred to the CNC from other clinics including the child neurology clinic located within the same hospital.

In the developmental program, offered at the Gothenburg CHCs, a check up at the age of 21/2 years is always offered. In Gothenburg the total population of 21/2-year-old children in 2010 (born in 2007 or in 2008) was estimated at 6,220 based on the numbers of the two birth years 2007 (6,022) and 2008 (6,418) at the end of 2010. Ninety-seven per cent of the 21/2-year-olds children (6,033) were reached by the CHC s according to statistics from the CHC

authority. According to the same statistics, 83% of the 6,033 were screened with the new routines for autism screening in 2010, corresponding to 80% of the total of 6,220 children. Thus, the total 2-year-old population available for the study was estimated to consist of these 5,007 children who were actually screened. The ratio of Swedish born parents (both parents born in Sweden) to foreign born parents (one or both parents born in another country) for this age group was 2.6:1 (72.1%/27.9%) (Statistics Sweden 2010).

Screening Procedure at the CHCs

During the first years of life 95.0–99.9% of all children are followed up at the CHCs in Gothenburg according to statistics from the CHC authority (Arvidsson et al. 2010). Nurses are responsible for the majority of the health check-ups and doctors are involved at certain key ages. The developmental program mostly includes a health visit at 21/2 years. In Gothenburg there were 49 different CHSs and a total of 139 nurses responsible for the developmental check-ups in 2010. A population screening for ASD was conducted at the 21/2-years-visit. Before the screening was started (as a pilot study from 2009), all nurses had been trained in the area of infant and toddler social interaction and communication developmental milestones, early symptoms of ASD and also in the use of some screening instruments (see below). They were encouraged to observe the children and listen to parental concern about child development not only at this screening point, but in connection with all contacts with families, and also to use the screening instruments beyond the routine age for screening.

Screening Instruments

The screening included the parent Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al. 2001) which was used in accordance with the recommended two-step screening model and algorithm form (Kleinman et al. 2008). The other screening instrument was a semi-structured five-item nurse observation of joint attention at the CHC visit (Appendix). Both these instruments had clear cut-off levels. Screen positivity for autism was defined as either a score above the M-CHAT algorithm after interview confirmation or a score of two or more failed items at the observation "joint attention". The validation of these screening instruments in Swedish child populations is the subject of a separate report, (Nygren et al. in progress 2011).

Many different factors influenced the already planned population screening at the 21/2 years check-up in 2010 in a negative way. There was a threat of pandemic influenza and for a period the focus and resources of the CHCs were on the vaccination of all children. A political plan implemented during the same year led to a change in the number of CHCs from 24 to 49. This of course, had consequences both for the families and for the CHC staff and possibly also for some of the results of the present study. In several cases the screening was delayed for some months and many children were missed for different reasons at this age. On the other hand, there was, in some cases, an earlier a suspicion of ASD leading to the use of the screening tools and referral for evaluations even before child age 2 years.

Diagnostic Procedure

Pathways to diagnosis and follow-up were established before the start of the study. The explicit goal was a completed evaluation of the child within 3–4 months at the CNC from the time that the suspicion of autism had been voiced. Interventions should be promptly delivered by habilitation services after a diagnosis of ASD had been made. Diagnostic criteria of the DSM-IV-TR (American Psychiatric Association 2000) would be used throughout (even though the term atypical autism would be used for cases of pervasive developmental disorder not otherwise specified).

A broad neuropsychiatric evaluation was conducted in every case referred from the CHC or other sources, including clinical psychiatric and medical examination made by an experienced medical doctor (checking the criteria of the DSM for disorders usually first evident in infancy or childhood, including those for pervasive developmental disorders), neuropsychological tests, developmental level (Griffiths) (Norberg et al. 1980), and the Vineland Adaptive Behavior Scales (Sparrow et al. 1984) completed at interview with a parent. The Autism Diagnostic Observation Schedule (ADOS) (Lord et al. 2000) was performed by experienced clinicians in all but three of the cases (due to problems attending the scheduled visit). Expert language assessments were done by a speech and language therapist in all cases. The Diagnostic Interview for Social and COmmunication Disorders (DISCO-11) (Nygren et al. 2009; Wing et al. 2002) was performed in two thirds of the cases, but was considered too cumbersome for parents with limited Swedish or English skills (plus a few had problems attending the very long scheduled visits for the several hour interview). The evaluation also included child observation made at preschool by an experienced special education teacher from the team (GWA).

All evaluations were performed by clinicians independently of each other. The final DSM-IV-TR diagnosis ("best estimate clinical research diagnosis") was based on all available evidence obtained at these evaluations.

Study Populations 2000 and 2005

The study populations of 2000 and 2005 consisted of children in Gothenburg diagnosed with ASD at the age of 2 years in 2000 and in 2005. The population of 2-year-old children was estimated at 4,871 in Gothenburg in 2000 based on the numbers of the two birth years 1997 (4,753) and 1998 (4,989). The population of same aged children in Gothenburg in 2005 was estimated at 5,250 based on the birth year of 2003 (5,068) and 2004 (5,431). The children had been diagnosed with ASD at the same centre, CNC, serving the whole city, and the diagnostic information was taken from the medical records.

Ethics

The study was approved by the Regional Ethics Committee in Gothenburg. Parents signed written informed participation consent forms.

Statistical Methods Used

ASD prevalence and 95% confidence intervals were calculated on the basis of the number of diagnosed cases divided by the number of individuals reached by the screening procedure 2010 (n = 5,007) and also for diagnosed cases of ASD divided by the number of the total estimated population (n = 6,220). For the comparison populations (2000 and 2005) the prevalence and 95% confidence intervals were calculated in the same way by the number of diagnosed cases of ASD divided by the number of the total estimated population (Table 2).

In order to test if the prevalence of ASD in 2010 differed from the prevalence in 2000 and 2005, Fisher's exact test was used.

In order to test if the rate of ASD children with foreign born parents in our population differed from the general population in Gothenburg, a binomial test was used.

Results

Prevalence Rate for ASDs in 2-Year-Old Children in 2010

Forty-nine children, all born in 2007 or 2008, were referred at the age of 2 years to the CNC with a suspicion of ASD. Two of these children had a diagnosed mental retardation and were referred by child neurologists from the local habilitation service for further evaluations with the suspicion of ASD. The other 47 children were all referred from the CHCs. Four of these 47 families refused to come for the in-depth assessment with their child, leaving a total of 45 children who were actually examined.

Table 1 ASD prevalence, total and for boys and girls separately in 2-year olds in study population 2010 (n = 5,007 screened children)

Diagnosis	Prevalence total % (n)	Boys % (n)	Girls % (n)
Autism	0.52 (26)	0.43 (22)	0.08 (4)
Atypical autism	0.28 (14)	0.20 (10)	0.08 (4)
All ASD	0.80 (40)	0.64 (32)	0.16 (8)

In addition to the referred and assessed children there were six children raising strong screening suspicion of ASD. In two of these cases the parents wanted to wait one more year for the evaluation, and in one case the family had moved abroad before the referral and assessment at the CNC was possible. In three other cases, the CHC had, for unknown reasons, not yet referred the children to the CNC at the end of 2010 when intake to the study was closed.

Forty (8 girls and 32 boys) of the 45 assessed "ASD suspected" children were actually given an ASD diagnosis after the full in-depth clinical assessment. This corresponds to a total ASD prevalence for 2 year-olds of 0.80% (Table 1).

Twenty-six individuals received the diagnosis of autistic disorder, and 14 were diagnosed as having atypical autism (or pervasive developmental disorder not otherwise specified). Four-teen of the children had ASD plus developmental delay or diagnosed mental retardation/learning disability (intellectual developmental disorder), and 24 were diagnosed as being in the normal range of intellectual functioning. In two cases the neuropsychological tests had not been completed (Table 2).

In 20/40 cases both parents were of Swedish descent and in the other 20 cases one (n = 4) or both (n = 16) of the parents had been born in another country. Thus, the ratio of Swedish to foreign born parents for the children with ASD was 1:1, which is significantly different, ($p = 0.005$) from 2.6:1 for this age group in the general population in Gothenburg (Statistics Sweden 2010).

Prevalence Rates for ASDs in 2-Year-Old Children in 2000 and 2005

Nine 2-year-olds had been diagnosed with ASD at the CNC in 2000 (6 with autistic disorder and 3 with atypical autism, 6/9 had mental retardation). This corresponds to a minimum 2000 population rate of ASD in 2-year-olds of 0.18%.

In 2005 only two 2-year-old children had been diagnosed with ASD at the CNC (both with autistic disorder and mental retardation). This corresponds to a minimum population rate of ASD in 2-year-olds of 0.04% in 2005 (Table 2).

Table 2 ASD prevalence and the developmental levels of children with ASD in the three study populations 2000, 2005 and 2010

Study population	Autism n (♂/♀)	Atypical autism n (♂/♀)	Individuals with normal developmental level n	ASD total n	ASD prevalence %	95% CI
2000	6 (6/0)	3 (1/2)	3	9	0.18	0.08–0.35
n = 4,871						
2005	2 (2/0)	0	0	2	0.04	0.01–0.14
n = 5,220						
2010	26 (22/4)	14 (10/4)	26	40	0.64[a]	0.46–0.87
n = 6,220					0.80	0.57–1.09
n = 5,007 screened						

[a] For this calculation, the total population of individuals was used as denominator rather than the total populations screened, so as to allow head-to-head comparison with rates reported for 2000 and 2005

Discussion

The increase in ASD prevalence rates reported over the last two decades most likely represents changes in the definitions, widening of diagnostic criteria and increased awareness both among professionals and the general public. Given the diversity of the ASD etiology (Coleman and Gillberg 2011), it cannot be ruled out that there are many, as yet, unknown factors that may also contribute to the increase, part of which could be a real, rather than apparent, rise in the "base rate" of ASD in the population. There is, for instance an over-representation of ASD in children from immigrant families (Dealberto 2011) and a corresponding, much higher than expected, rate of ASD in children with extremely low birth-weights (Johnson et al. 2011).

The prevalence rate of 0.80 in 2-year-old children in the present study must be considered as a minimum rate of ASD in the general population. Only about 80% of the 2-year-olds were screened for ASD; 20% were neither screened nor assessed. There were several reasons for this attrition, most of which appeared to be related to organizational and random accidental events, including the unforeseeable acute proposed and media-exaggerated risk of outbreak of swine flu, and the sudden administrative change in the delivery of CHC services in the city of Gothenburg coinciding with the ASD screening. Among the families that were not reached by the screening, were several spending longer periods of time in their native sub-Saharan African countries. Other families were not reached despite several invitations to the CHC. Some other children were not screened or examined at all at the CHCs because they already were followed up by other specialists for developmental and neurological disorders and other chronic diseases. In all these subgroups from the "attrition cohort", the rate of ASD would, if anything, be higher than in the screened/assessed group.

There were also ten children identified in the CHC screening with a strong suspicion of ASD, who were never assessed in depth. The data from screening and the developmental histories for the ten individuals indicated a probable ASD diagnosis in all of them. If these children had been included the prevalence rate for ASD for 2-year-old children would have been 1%.

The rates of diagnosed ASD in 2-year-olds for 2000 and 2005 (0.18 and 0.04%, respectively) were strikingly different from the approximately one per cent of the 2-year- olds with an ASD diagnosis in 2010. The majority of the children diagnosed with ASD in 2010 had a developmental level within the normal range and only 35% were diagnosed with mental retardation or developmental delay. This was in contrast to results of the earlier study populations and to the results from our group from the 1980s in which 75% of children with ASD had mental retardation (Gillberg et al. 1991).

One of the reasons that the present study was launched was the clinical impression that the age of autism diagnosis had gradually gone up in the early 2000s after a steady decrease in diagnostic age form the 1970s through to the mid 1990s (Gillberg 1984; Gillberg et al. 1991, 2006; Steffenburg and Gillberg 1986). We believe that this could have been caused by gradual attenuation rather than augmentation of "autism awareness" among CHC staff and hence later referral for diagnosis. Before the present prevalence study was performed, a massive educational effort was directed at CHCs throughout Gothenburg with the aim of getting each individual CHC nurse sufficiently up-to-date regarding the presentation of ASD in very young children to make her/him comfortable in making reasonable decisions regarding need for referral for ASD assessment. It would appear that this effort, taken with the introduction of general population formal screening, the M-CHAT and the nurse observation of "joint attention", was very successful and must have accounted for much of

the dramatic change regarding the increase of referral of very young children with a suspicion (and documented diagnosis of) ASD.

Appendix

Toddler observation of joint attention.

1. Reacts to own name (turns to person addressing)?
2. Does the child try to establish eye-contact with you?
3. Does the child gaze at something that you point to further away in the room?
4. Does the child use index-finger to point at something (e.g. in a book)?
5. Does the child interact with you or parent in pretend play (e.g. during feeding a doll, putting the doll to bed, does the child use eye contact to monitor that you are watching)?

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