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ORIGINAL PAPER

Changes in Prevalence of Autism Spectrum Disorders in 2001–2011: Findings from the Stockholm Youth Cohort

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Abstract In a record-linkage study in Stockholm, Sweden, the year 2011 prevalence of diagnosed autism spectrum disorders (ASD) was found to be 0.40, 1.74, 2.46, and 1.76 % among 0–5, 6–12, 13–17, and 18–27 year olds, respectively. The corresponding proportion of cases with a recorded diagnosis of intellectual disability was 17.4, 22.1, 26.1 and 29.4 %. Between 2001 and 2011, ASD prevalence increased almost 3.5 fold among children aged 2–17 years. The increase was mainly accounted for by an eightfold increase of ASD without intellectual disability (from 0.14 to 1.10 %), while the prevalence of ASD with intellectual disability increased only slightly (from 0.28 to 0.34 %). The increase in ASD prevalence is likely contributed to by extrinsic factors such as increased awareness and diagnostics.

Keywords Autism spectrum disorders · Intellectual disability · Prevalence · Time trend · Stockholm · Sweden

Introduction

Studies on the prevalence of autism spectrum disorders (ASD) set up for research purposes and including population screening procedures with subsequent diagnostic tests, suggest that the current ASD prevalence among children is approximately 1 % (Baird et al. 2006; CDC 2014), and even approaching 2 % (Baron-Cohen et al. 2009) to 3 % (Kim et al. 2011). A similar study design indicates a current ASD prevalence among adults at approximately 1 % (Brugha et al. 2011), however studies on adult prevalence are sparse. Furthermore, global ASD prevalence estimates have increased substantially over recent decades (Elsabbagh et al. 2012), and over shorter, current time frames (Baird et al. 2006; Pinborough-Zimmerman et al. 2012; CDC 2014; Ouellette-Kuntz et al. 2014). Although increases in the identified prevalence of ASD have been noted at all levels of intellectual ability (Baird et al. 2006), they have been more pronounced for those with average or above-average IQ (Elsabbagh et al. 2012; Saemundsen et al. 2013; CDC 2014).

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We here report on the 2011 year prevalence of diagnosed ASD among children and young adults in Sweden. We also report age-specific trends among children over a recent 10 year period. We take advantage of a recent update of the Stockholm Youth Cohort (SYC), a total population study with multiple source case ascertainment in Sweden where child developmental screening is universal. We present findings for ASD with and without comorbid intellectual disability from analyses stratified according to socio-demographic characteristics to further inform policy making and provide etiological insight.

Methods

Study Population

The SYC is a longitudinal record-linkage study comprising all children aged 0 through 17 years resident in Stockholm County at any time from 2001 through 2011 (N = 735,096). It includes prospectively compiled data on children and their first-degree relatives through record linkage with a range of Swedish national and regional health and administrative registers; a full description of the study design and sources of data is available elsewhere (Idring et al. 2012). The primary key to record linkage was the unique personal identification number assigned to each Swedish citizen at birth, or upon arrival in Sweden for immigrants (Ludvigsson et al. 2009). Ethical approval was obtained from the research ethics committee at Karolinska Institutet.

ASD Diagnosis and Validity

Annual ASD case status was ascertained using national and regional registers covering all the pathways of ASD diagnosis and care in Stockholm County (Idring et al. 2012) that we were aware of for each study year 2001–2011. The registers included (with the respective case proportion in 2011 ascertained from each source in parentheses): (1) the VAL database—a register providing data on public health care services in Stockholm County, including diagnostic codes according to ICD 10 and information on clinics providing care (80.4 %), (2) the Habilitation Register, providing data on utilization of Stockholm County Habilitation services according to type of disability, such as pervasive developmental disorders and intellectual disability (69.4 %), (3) Clinical database for Child and Adolescent Psychiatry in Stockholm, including child- and adolescent in—and outpatient care within Stockholm County, coded according to DSM-IV until 2008, and according to ICD-10 since 2009 (60.7 %), and (4) the National Patient Register, comprising data on inpatient care since 1973, and outpatient visit to specialist (doctors) since 1997, including diagnoses according to ICD 7–10 (13.3 %). Diagnosis of ASD was ascertained from these registers as a recorded diagnosis of 299 or F84 according to ICD-9 (World Health Organization 1977) and ICD-10 (World Health Organization 2005), respectively, and 299 according to DSM-IV, and supplemented using the Habilitation Register. The major strength of a multisource ascertainment approach is that individuals with ASD may have a variety of health and social care needs; not all individuals receive a diagnosis in any one setting or are in touch with any given service at all times. This is evident in the partial, rather than complete overlap between the various registers.

Information on the age at first diagnosis of ASD was not available from the registers. Cases with ASD were divided into two groups depending on a comorbid diagnosis of intellectual disability (defined as IQ <70 and functional impairment by international and Swedish norms). Diagnoses of intellectual disability were determined through ICD classification (code 317–319 in ICD-9 and F70–79 in ICD-10; World Health Organization 1977, 2005) in the National Patient Register, the VAL database, and the Clinical Database for Child and Adolescent Psychiatry since 2009; DSM group-level classification (code 317–319; American Psychiatric Association 1994) in the Clinical Database for Child and Adolescent Psychiatry in Stockholm before 2009, and supplemented using the Habilitation Register which categorizes service recipients as having autism with or without intellectual disability.

A previous validation by the research group of ASD case ascertainment through review of 177 randomly sampled medical records found that 96.0 % cases were consistent with an ASD diagnosis. Final ASD case status was determined through (1) a medical-note documented diagnosis of ASD with or without ID according to ICD-9, ICD-10 or DSM-IV and at least one of the remaining criteria (2) documented evidence of use of a structured diagnostic process, (3) evidence of referral to health and/or community services related to ASD with or without ID (Idring et al. 2012). In a comparison of ASD cases identified the SYC against information from a national population-based study of twins (the Child and Adolescent Twin Study in Sweden—CATTS; Anckarsater et al. 2011), 85.2 % of cases identified in the SYC were confirmed as ASD according to information from the CATTS (Idring et al. 2012).

The prevalence of ASD for the 1990–2009 birth cohorts during 2001 through 2011 is shown only for 2–17 year olds because no prevalent cases were discovered for 0 through 1 year olds, while estimates for adults during the first years of surveillance might be deflated by truncation, i.e. key registers used for case ascertainment being started in 1997 and 2001, respectively, may have deflated the observed prevalence among older children.

Socio-demographic Characteristics

Biological parents and their dates of birth were identified from the Multi-generation Register. Data on parental country of origin were obtained from the Register of Total Population, and categorized as the mother born in Sweden, or abroad in country of low or high human developmental index (HDI), respectively. The latter was determined using the UNDP HDI, a composite indicator of development derived using indicators of life expectancy, education and income (UNDP). Maternal country of birth was used because maternal and paternal countries of birth were largely identical in children with both parents were born abroad. Socio-demographic data was extracted from the Integrated Database for Labor Market Research, which provides information on income, level of education and occupational status, by year of childbirth, or as close as possible. Individualized disposable family income at time of birth, including social benefits, was calculated after deductions of taxes and is adjusted for family size. To account for inflation, family income was categorized into quintiles according to the child's birth year. The highest educational achievement of the mother or father of the child and classified as number of years of completed education into up to 9 years (primary school), 10–12 years (high school) and >12 years (secondary education).

Statistical Analysis

The 2011 prevalence of ASD by comorbid intellectual disability and socio-demographic characteristics was estimated in the whole study population. Annual prevalence of ASD with and without intellectual disability among 2–17 year olds during the study period 2001 through 2011 by birth year, sex, country of origin, disposable family income at time of birth and highest level of parental education was calculated by dividing cases by the total number of residents at the end of follow-up in 2011. The 95 % confidence intervals (CI) around these proportions were calculated using the Clopper–Pearson method.

Results

Year 2011 ASD Prevalence Among 0–27 Year Olds

The 2011 distribution of ASD cases overall, and by intellectual disability in the study population by socio-demographic characteristics is described in Table 1. We identified a total of 11,330 individuals with ASD aged 0–27 years in 2011, of whom 2,900 (25.6 %) had an intellectual disability. The prevalence of ASD was 1.44 % (95 % CI 1.41–1.47 %) among children aged 0–17 years and increased with increasing age, such that it was highest among teenagers (2.46 %; 95 % CI 2.38–2.55 %). Similar trends were observed regardless of intellectual disability. The prevalence of ASD among young adults aged 18–27 years was 1.76 % (95 % CI 1.71–1.81 %). The male:female ASD prevalence ratio was 2.3:1 and similar regardless of intellectual disability. The sex ratio decreased with age, from 3.3:1 among 0–12 year olds, to 2.4:1 and 1.9:1 in teenagers and adults, respectively. This trend was more prominent in cases without intellectual disability, where the average sex ratio decreased from 3.1:1 in the child population, to 1.8:1 among adults.

Autism spectrum disorders was found to be more prevalent among certain groups of migrants. Among 2nd generation migrants, especially if descending from countries of low HDI, the prevalence of ASD with intellectual disability was significantly higher compared to individuals born in Sweden and 1st generation migrants. In contrast, ASD without intellectual disability was significantly less prevalent among 2nd generation migrants from countries of low HDI, and 1st generation migrants compared to children of native Swedes and 2nd generation migrants from high-HDI countries.

Autism spectrum disorders was found to be less prevalent with increasing familial levels of income, which pertained especially to ASD with intellectual disability. Similarly, the prevalence of ASD was found to decrease with increasing level of parental education, regardless of intellectual disability.

Prevalence of ASD Among 2–17 Year Olds in 2001–2011

Among children aged 0–17 years, ASD prevalence increased by almost 3.5 fold, from 0.42 % in 2001 to 1.44 % in 2011. Furthermore, the prevalence of ASD without intellectual disability increased by almost eight-fold, from 0.14 to 1.10 %, while the prevalence of ASD with intellectual disability remained relatively unaltered with only a slight increase, from 0.28 to 0.34 %.

The birth cohort-specific prevalence of ASD with and without intellectual disability during 2001 through 2011 is displayed according to age in Fig. 1b, c, respectively.

A consistent increase of ASD without, but not with, intellectual disability with subsequent (younger) birth cohorts was observed (Fig. 1b, c). Furthermore, the occurrence of diagnosed ASD did not appear to level off with increasing age within birth cohorts, regardless of intellectual disability.

Increases in prevalence of ASD across birth cohorts were more prominent with increasing age. For example, among 8-, 14- and 16-year olds, ASD prevalence increased approximately three, four and sixfold, during the 10 year

Table 1 The year 2011 distribution of cases with ASD with and without intellectual disability in the Stockholm Youth Cohort, according to socio-demographic characteristics

	All	ASD		ASD with intellectual disability		ASD without intellectual disability	
	N	N	% (95 % CI)	N	% (95 % CI)	N	% (95 % CI)
Overall	735,096	11,330	1.54 (1.51–1.57)	2,900	0.39 (0.38–0.40)	8,430	1.15 (1.13–1.17)
Age (*years*)							
0–5	179,655	712	0.40 (0.37–0.43)	124	0.06 (0.06–0.08)	588	0.33 (0.30–0.36)
6–12	190,512	3,313	1.74 (1.68–1.80)	731	0.38 (0.35–0.41)	2,582	1.36 (1.31–1.41)
13–17	125,687	3,096	2.46 (2.38–2.55)	807	0.64 (0.60–0.69)	2,289	1.82 (1.75–1.90)
18–27	239,242	4,209	1.76 (1.71–1.81)	1,238	0.52 (0.49–0.55)	2,971	1.24 (1.20–1.29)
Sex							
Female	358,479	3,297	0.92 (0.89–0.95)	826	0.23 (0.21–0.25)	2,471	0.69 (0.66–0.72)
Male	376,617	8,033	2.13 (2.08–2.18)	2,074	0.55 (0.53–0.57)	5,959	1.58 (1.54–1.62)
Country of origin							
Swedish-born individual and parents	432,047	6,964	1.61 (1.57–1.65)	1,424	0.33 (0.31–0.35)	5,540	1.28 (1.25–1.31)
Individual born in Sweden, mother abroad (high HDI)	78,288	1,404	1.79 (1.70–1.89)	353	0.45 (0.41–0.50)	1,051	1.34 (1.26–1.42)
Individual born in Sweden, mother abroad (low HDI)	145,790	2,130	1.46 (1.40–1.52)	834	0.57 (0.53–0.61)	1,296	8.9 (8.4–9.4)
Individual born abroad (high HDI)	21,012	266	1.27 (1.13–1.43)	87	0.41 (0.33–0.51)	179	0.85 (0.73–0.98)
Individual born abroad (low HDI)	51,421	474	0.92 (0.84–1.01)	182	0.35 (0.30–0.40)	292	0.57 (0.51–0.64)
Disposable income, *quintiles*							
1 (Lowest)	145,123	2,067	1.42 (1.36–1.48)	708	0.49 (0.46–0.53)	1,359	0.94 (0.89–0.99)
2	145,051	2,632	1.81 (1.74–1.88)	704	0.49 (0.46–0.53)	1,928	1.33 (1.27–1.39)
3	144,538	2,447	1.69 (1.62–1.76)	536	0.37 (0.34–0.40)	1,911	1.32 (1.26–1.38)
4	144,190	2,111	1.46 (1.40–1.52)	444	0.31 (0.28–0.34)	1,667	1.16 (1.11–1.22)
5 (Highest)	144,096	1,812	1.26 (1.20–1.32)	417	0.29 (0.26–0.32)	1,395	0.97 (0.92–1.02)
Parental education							
Primary school	115,686	2,017	1.74 (1.67–1.82)	608	0.53 (0.49–0.57)	1,409	1.22 (1.16–1.28)
High school	292,380	5,036	1.72 (1.67–1.77)	1,269	0.43 (0.41–0.45)	3,767	1.29 (1.25–1.33)
Secondary school	308,633	3,983	1.29 (1.25–1.33)	921	0.30 (0.28–0.32)	3,092	0.99 (0.96–1.03)

period, respectively. In addition, the proportion of cases without intellectual disability steadily increased; from 21.7 to 80.6 % among 8-year olds, from 45.8 to 75.8 % among 14-year olds and from 33.3 to 74.3 % among 16-year olds.

No significant differences in changes of ASD prevalence with and without ID were observed across birth cohorts by either sex, country of origin, and parental education (results not shown).

Discussion

Using a multisource case ascertainment methodology we found that 1.44 % of 0–17 year olds, and 1.76 % of 18–27 year olds in the SYC had a recorded diagnosis of ASD by the end of 2011, of which 23.3 and 29.4 % also had a recorded diagnosis of intellectual disability, respectively. In the population aged 0–17 years, the proportion with diagnosed ASD increased with age, such that ASD prevalence was highest among teenagers (at 2.46 %). The proportion of children identified with an ASD differed by sex, age, country of origin, familial income and education. The prevalence of ASD among 0–17 year olds increased almost 3.5 fold between 2001 and 2011, accounted mainly for by a sharp increase of ASD without intellectual disability. While more prominent increases of diagnosed ASD during this period were found with increasing child age, no significant differences were observed by sex and other socio-demographic characteristics. Results indicate that the identified proportion of individuals with ASD is not levelling off through young adulthood.

Despite generally considered superior, ASD prevalence estimates based on active population screening and consequent diagnostic tests may be limited by incomplete sampling/coverage and low participation rates. Moreover, some screening approaches are directed towards

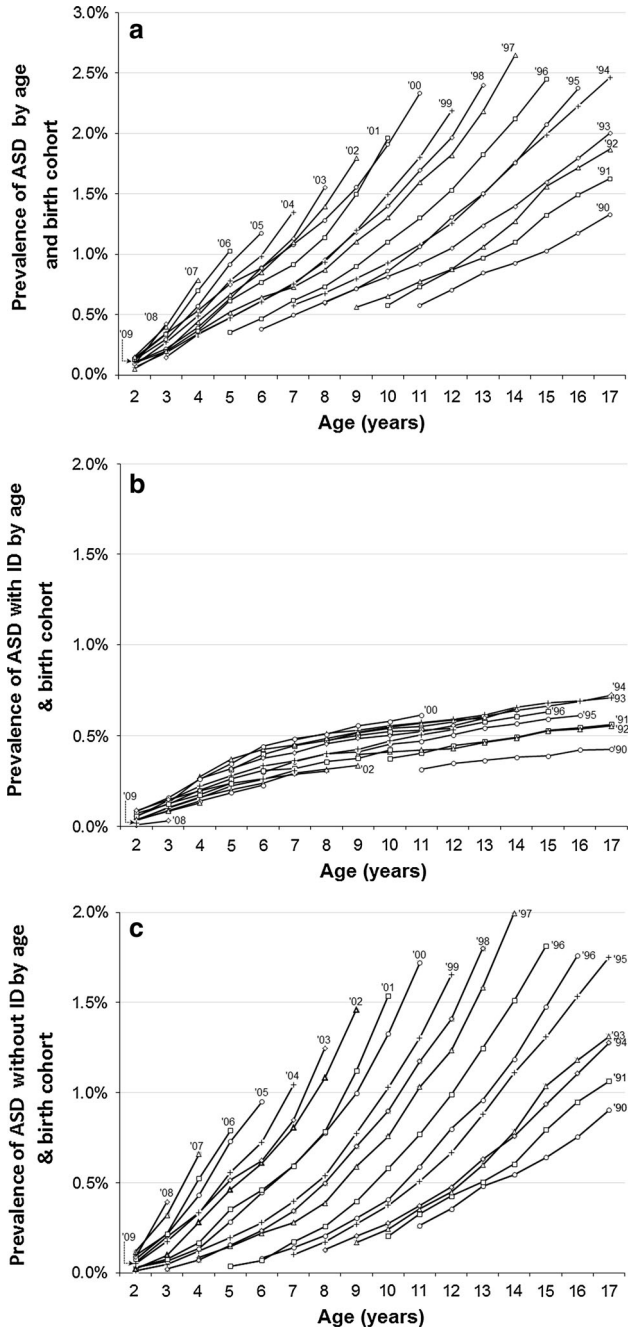

Fig. 1 Prevalence of ASD overall (**a**), with (**b**) and without intellectual disability (**c**) among 2–17 year olds in the Stockholm Youth Cohort in 2001–2011, by age and birth cohort. *Note*: Although birth cohorts from 1990 to 2009 are displayed, only certain cohort curves are labeled due to overlapping curves

populations with higher probability of ASD such as children with special education needs, rather than the general population; therefore prevalence estimates from such studies should be considered as minimum figures of ASD prevalence (Baird et al. 2006). Studies relying on health and/or education service registers for case ascertainment instead provide better coverage, although underestimation is likely as some cases remain unidentified by services. Nevertheless, register-based studies in settings where service systems are universal and well-developed, and where multiple sources record diagnostic data are important surveillance tools (CDC 2014). Among individuals aged 4 years and above, we found similar proportions of ASD cases in comparative age groups in studies from the US (Nicholas et al. 2009; CDC 2014) and the UK (Baron-Cohen et al. 2009) based on active screening and diagnostic evaluations in populations with identified special education needs, symptoms associated with ASD or comorbid conditions. A similar study approach was used alongside with screening of a general population sample to derive the highest ASD prevalence estimate to date, 2.64 % among 7–12 year olds (Kim et al. 2011), which is comparable to our finding among teenagers. In contrast, lower proportions of ASD cases in comparative age groups were reported in recent studies from UK, Norway, Denmark, Sweden and Finland relying on case ascertainment from medical registers only (Suren et al. 2012; Taylor et al. 2013; Atladottir 2014), illustrating the advantage of our multisource case ascertainment strategy. Although prevalence estimates in our adult population may have been deflated by truncation, i.e. key registers used for case ascertainment being started in 1997 and 2001, respectively, they are higher than the 1 % identified in a UK adult population which also described that most affected adults were unidentified within services (Brugha et al. 2011).

Similarly, results from other recent studies using combined population screening and diagnostic procedures were comparable to our results concerning the proportion of ASD cases with intellectual disability (CDC 2014) and the male:female ratio (Baird et al. 2006; Kawamura et al. 2008; Kim et al. 2011). In contrast, the sex ratio was higher in a UK and Norwegian medical register-based studies (Suren et al. 2012; Taylor et al. 2013). Our results of higher ASD prevalence among children of lower socio-economic background are in line with recent studies from countries with universal health care systems such as Japan (Fujiwara 2014), Canada (Dodds et al. 2011), England (Emerson 2012), Denmark (Larsson et al. 2005) and Sweden (Rai et al. 2012). However, these findings are not concordant to multiple studies from the USA which instead have reported an association between increasing socio-economic status and offspring ASD (Croen et al. 2002; Bhasin and Schendel 2007; Durkin et al. 2010; Fountain et al. 2011; Windham et al. 2011). It is thought that US findings are influenced by better access to healthcare among individuals of high SES status in the non-universal healthcare system in the USA. Similarly, disparities in access to services and/or ascertainment and diagnostic bias have been thought to contribute to lower prevalence of ASD without intellectual disability among individuals of migrant background from

developing countries previously reported from the Netherlands (van der Ven et al. 2013) and Sweden (Haglund and Kallen 2011; Magnusson et al. 2012), a finding observed also in the current study. Our finding of ASD with intellectual disability being more prevalent among children born to migrant parents is in line with recent studies from the USA (Becerra et al. 2014), and several European countries (Keen et al. 2010; Haglund and Kallen 2011; Magnusson et al. 2012; Lehti et al. 2013; van der Ven et al. 2013; Bolton et al. 2014). However, further population-based studies are needed to disentangle the mechanisms underlying associations between ethnic origin, migration and ASD.

In a previous validation study, we previously found that the median age at diagnosis of ASD in the SYC was 8 years (Idring et al. 2012), which is substantially higher than the median age at first diagnosis commonly reported (CDC 2014), indicating underascertainment of ASD among preschool-aged children in the SYC. Despite universal and regular developmental screening in Swedish child healthcare centers (Stockholm County Council 2012), a recent Swedish study reported that symptoms of ASD among toddlers have either not been noticed or, if noticed, lead to referral for further diagnostic assessment not until years later (Nygren et al. 2012). Thus, the 0.1 % estimate of ASD among 2 year olds by year 2011 in the SYC is lower than the 0.8 % reported from the aforementioned study, which included targeted population screening procedures with subsequent diagnostic tests (Nygren et al. 2012). Similarly, higher rates of diagnosis resulting from screening procedures may have contributed to the 1.8 % ASD prevalence among preschool-aged children in a Japanese study (Kawamura et al. 2008).

The relatively high age at diagnosis of ASD, particularly ASD without intellectual disability in the SYC (Idring et al. 2012) likely contributes to ASD prevalence peaking first in teenagers. While greater symptom severity and parental concern contribute to an earlier diagnosis of ASD (Daniels and Mandell 2013), individuals with socio-communicative impairments but no significant delays in language, cognitive and adaptive development may instead be first recognized when demands for social communication skills overwhelm their abilities. In fact, studies of age at ASD diagnosis have consistently found that such ASD subtype is diagnosed later than other ASD (Daniels and Mandell 2013). Many individuals with ASD may therefore be diagnosed first in adolescence or adulthood. Furthermore, co-occurring psychiatric disorders, which are common in adolescents with ASD without intellectual disability (Hurtig et al. 2009; Mattila et al. 2010), have been associated with later age at ASD diagnosis (Hurtig et al. 2009; Levy et al. 2010; Mattila et al. 2010).

The increasing trends in prevalence of ASD over recent time frames observed in our study have also been described in many countries, including the US (Blumberg S 2013; CDC 2014), Canada (Ouellette-Kuntz et al. 2014), Iceland (Saemundsen et al. 2013), Denmark, Finland, Sweden, Western Australia (Atladottir 2014) and Japan (Kawamura et al. 2008). Similarly, increases have globally been more pronounced for those with normal IQ (Elsabbagh et al. 2012; Saemundsen et al. 2013; CDC 2014). Recent reports from multiple countries suggest that this trend is not limited to ASD, but also other neuropsychiatric disorders (Atladottir 2014). Because identical case ascertainment methodology was applied throughout the study period 2001–2011, the increase in ASD prevalence cannot be explained by variations in internal measurement. Instead, it is possible that the lion share of the increase is contributed to by increased awareness of developmental disorders (Liu et al. 2010), improved service availability, including substantially higher rates of referrals for, and completed diagnostic ascertainments between 2007 through 2011 among children in Stockholm County (Lundberg 2012). Increasing awareness and rates of diagnostic ascertainments likely contributes to that previously unidentified cases without ID are diagnosed; in fact, findings from South Korea where lower prevalence of ASD with intellectual disability were noted in the general, non-clinical population sample indicate that children with ASD and normal IQ may not be identified by health care, education and social support services (Kim et al. 2011). Although increases in ASD prevalence during the study period were noticed among all children older than 3 years in our study, the increase was more pronounced with older age, in line with previous findings of higher median age at diagnosis of ASD without intellectual disability in the SYC (Idring et al. 2012). Decreased age at ASD diagnosis has been speculated to contribute to increased prevalence (Wazana et al. 2007; Hertz-Picciotto and Delwiche 2009; Shattuck et al. 2009; Parner et al. 2011), however we lack empirical data to examine changes in age at first diagnosis during the study period.

While speculating that a large share of the observed increase in the prevalence of ASD is likely due to increased awareness and ascertainment rates, we cannot rule out a true increase in incidence. Similarly, effects of changes in diagnostic criteria and the inclusion of outpatient data could not explain a considerable part of ASD prevalence increase in Denmark (Hansen 2014). Changes in potential risk factors for ASD, including pre-, peri- and neonatal factors (Gardener et al. 2009, 2011) may contribute to increased incidence. However, the contribution of many of these factors to the observed ASD increase has been arbitrated as minimal (Schieve et al. 2011). Instead, findings from a California study of age, period, and cohort effects

were more consistent with changes in diagnostic practices and heightened awareness as potential explanations to the observed ASD increase, than younger age at diagnosis or broad environmental factors (Keyes et al. 2012).

Regardless of whether the recent ASD prevalence increase are contributed to by increased awareness, changes in diagnostic practices, a true change in prevalence, or all of these factors, the increase may be interpreted as a sign of increased awareness of traits that potentially makes it more difficult for an individual to reach developmental goals. Hence, our findings underline the need of parallel adaptations to provide support for this—and other groups of individuals with neuropsychiatric disorders—within the educational—and health system as well as the labor market. Although the thorough case ascertainment design used in our study provides ASD prevalence estimates comparable to more detailed studies including also general population screening procedures, there are indications that ASD cases without intellectual disability of migrant background and ASD cases among preschool-aged children are under-ascertained.

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