Description of a Danish Nationwide Survey of Adolescents and Adults Diagnosed With Autism Spectrum Disorders in Childhood

The AutCome Study

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Published in:
Journal of Mental Health Research in Intellectual Disabilities

DOI (link to publication from Publisher):
10.1080/19315864.2018.1497109

Publication date:
2018

Document Version
Accepted author manuscript, peer reviewed version

Title:

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Abstract

A nationwide survey of children diagnosed with autism spectrum disorders (ASD) was conducted with the aim of exploring outcomes in adolescence and adulthood. The purpose of this paper is to evaluate the representativeness of the study population and to describe the study population. In total, 1734 parents and 933 individuals with ASD returned the questionnaire which included information from individuals with ASD and their parents. The study population was found to be representative of individuals diagnosed with ASD in childhood at Danish psychiatric hospitals. Compared to other ASD populations, lower rates of intellectual disability, psychiatric comorbidity, language difficulties, and epilepsy were found.

Introduction

Outcome for people with autism spectrum disorders (ASD) requires further investigation as no clear picture has developed, despite several outcome studies (Billstedt, Gillberg, & Gillberg, 2005; Howlin, Goode, Hutton, & Rutter, 2004). Questions that still need answering include, for example, whether outcome has improved generally in recent decades. Studies often estimate outcome by applying an overall outcome measure first introduced by Rutter, Greenfeld and Lockyer (1967) focusing on educational level, employment history, the quality of social relationships, and independent living. The conclusion from reviews on this general, overall outcome measure is that the overall outcome for people with ASD was poor for about half of study populations (Henninger & Taylor, 2013; Howlin & Moss, 2012; Steinhausen, Mohr Jensen, & Lauritsen, 2016). However, case ascertainment most likely impacts on the results derived from, in particular, older ASD outcome studies, as prior to the use of ICD-10 (World Health Organization, 1992) and DSM-IV (American Psychiatric Association, 1994), only more severe cases of ASD were diagnosed (Kaboski, McDonnell, & Valentino, 2017). Furthermore, a recent review by Howlin and Magiati (2017) highlights the varying findings reported when studying outcome in individuals with ASD, and as discussed in the review this may relate to, for example, the heterogeneity of the cohorts studied. Yet, it is also worth discussing what defines a good outcome for people with ASD. Obviously, the way outcome is defined and operationalized can influence the conclusions made. This is illustrated by Billstedt, Gillberg and Gillberg (2005; 2011), who re-evaluated the outcome of their sample by moving from the general overall outcome definition to a definition of outcome based on the fit between the individual with ASD and his/her environment, for example whether caregivers had specific knowledge about autism, or whether daytime activity corresponded to the level of capacity of the individual with ASD. This shift improved the outcome results. In line with this, an important discussion is whether a good outcome should have roots in normative standards like the traditional definition of overall outcome, or whether it should reflect aspects of well-being and/or quality of life (QoL). Sometimes people with ASD will define a good life as meeting the normative standards of the society in which he or she lives, but this may not always be the case. In any case, it can be argued that it is necessary to look at outcome from

multiple perspectives in order to capture the big picture of the outcome of individuals with ASD.

Furthermore, the first cohort of children diagnosed with ASD consistently and in a measureable manner according to diagnostic criteria and available assessment tools has only recently reached adulthood (Kaboski et al., 2017). Additionally, the necessity of recruiting a large sample when studying outcome in ASD must be emphasized. Individuals with ASD display a high degree of heterogeneity when it comes to, for example, functional abilities such as language and intelligence, and also the presence of symptoms compatible with comorbid psychiatric disorders (Georgiades, Szatmari, & Boyle, 2013). Thus, recruiting a large and representative sample increases the probability of capturing the diversity in outcome found among people with ASD.

With the aim to extend and update existing knowledge about outcome of children diagnosed with ASD in childhood, a Danish nationwide survey entitled the AutCome study were conducted. In the questionnaires conducted for the survey, information on the adolescents and young adults with ASD was gathered from as well individuals with ASD as their parents, applying a multi-faceted perspective on outcome including, for example, adaptive behavior, QoL and educational and/or occupational status. This paper aims to compare the responders of the questionnaire with non-responders using data from Danish national public registers. Comparisons between these two groups yield information about the representativeness of the study sample. Additionally, a description of the study sample with ASD with respect to basic demographics and comorbid disorders and conditions is provided.

Method

Study population

Danish adolescents and adults born in the period 1990–99 and diagnosed with ASD before the age of 14 years were invited to participate in this survey together with their parents. The individuals invited were identified in the Danish Psychiatric Central Research Registry (DPCRR) (Mors, Perto, & Mortensen, 2011) as probands with one of the following diagnoses according to ICD-10: F84.0 infantile autism; F84.1 atypical autism; F84.5 Asperger's syndrome; and F84.8 other pervasive developmental disorder (other PDD). Participants were aged between 16 and 26 years when completing the survey. We invited adolescents/adults with ASD via their parents. Consequently, we could only invite individuals with ASD whose parent(s) were alive and had a current Danish valid postal address. Owing to Danish laws of privacy, only families – where the parent(s) had the custody of the child(ren) at the time of diagnosis of ASD – were invited. A small group could not be invited for the above reasons, however, as illustrated in Figure 1, the large majority of the cohort of Danish adolescents and adults registered with a diagnosis of ASD and their families was invited.

[**insert Figure 1**]

Survey procedure

Individuals with ASD and their parents were invited by mail to participate in the online survey with a unique login to as well the parents as the adolescents/adults with ASD enabling completion of a parental questionnaire and a self-report questionnaire. It was clearly described that participation in the survey was non-compulsory. Parents could choose to complete the questionnaire together or alone. Parents were allowed to assist their youth/adult child in completing the survey, but it was underlined that their youth/adult child should decide how to answer the

questions themselves. Support in completing the questionnaires was available by phone and e-mail, and a reminder was sent out once by mail. Responders were encouraged not to leave any item unanswered. During the phase of preparing the questionnaires, they were evaluated by adults with expertise in the field of ASD or the Danish language (n=6) and revised according to their comments.

Ethics

The reason for inviting the individuals with ASD through their parents was that some children and adolescents diagnosed with ASD, according to our clinical experience, were known not to be aware of their diagnosis, which also was found in a follow-up study by Cederlund et al. (2008). Furthermore, parents had the option of rejecting the invitation on behalf of their child in the case that it would be too stressful for their child to complete the questionnaire.

The study was registered at The Danish Data Protection Agency (record no. 2008-58-0028). The Danish Health Data Authority provided the parental addresses used to invite the study population. Permissions to use the instruments and scales were obtained prior to including the selected scales and instruments in the online survey, and data were anonymized prior to statistical analysis.

Information sources for the AutCome study

In the AutCome study, data were gathered from the survey (i.e., the self-report questionnaire and the parental questionnaire). Furthermore, data from the Danish national registers were gathered, primarily covering sociodemographic information. The linkage between survey data and register data was performed by Statistics Denmark.

To minimize the workload on the individuals with ASD, the self-report questionnaire covered QoL only. The parental questionnaire was comprehensive, covering different areas of outcome and related factors: adaptive behavior; QoL; schooling, education and occupation; behavioral problems and other difficulties, including psychiatric comorbidity; autistic symptomatology; support and services; and parent empowerment. In text boxes throughout the questionnaire spaces were provided to write comments concerning the topics addressed.

Register data used for comparison of responders and non-responders of the survey

In order to evaluate the representativeness of the respondent group (depicted in Figure 1), information for the invited cohort was gathered from the Danish national registers covering particularly sociodemographic variables. An overview of the registers, variables and composite groups of variables used in this study is provided in Table 1. Parental information included current age, highest completed education, and place of living according to geographical regions in Denmark and population density. A variable about main occupation covering the main source of income was gathered for both the individual parent and the parental household, for example whether the main income originates from a job at the labor market or from social security benefit (see Table 1). For individuals with ASD, information on age, sex, age of diagnosis and type of first ASD diagnosis was derived from the DPCRR. The number of visits to psychiatric hospital departments were also derived from the DPCRR, including both inpatient and outpatient care. Psychiatric care or a psychiatric hospital visit was defined as the period between date of admission and date of discharge at a psychiatric department.

[insert Table 1]

Survey data used to describe the study population

Information from the parental questionnaire was used to describe the study population. Information about the current ASD diagnosis and current psychiatric comorbidity of their child was collected by asking the parents to choose from a list of diagnoses according to ICD-10 or to write the diagnosis/diagnoses themselves. With regard to intellectual disability (ID), the parents were asked to mark the presence of ID (yes; no; unsure) and if present the severity of ID. Furthermore, parents marked the presence of different conditions like epilepsy, and language, motor, vision, and hearing impairment. Specifically, the following response options were available for each condition: epilepsy (yes; previously only; no; unsure); language (normal or near language; no age-appropriate language use/only speaking sometimes; nearly no or no vocalization at all; unsure); motor impairment (yes; no; unsure); blindness or very reduced vision (yes; no; unsure); and deafness or severe hearing impairment (yes; no; unsure). Furthermore, parents were asked to evaluate the adequacy of the current support/service available for the family and/or the individual with ASD, and three categories were made: 1) sometimes/always adequate; 2) inadequate; 3) support/service not necessary.

Statistical Analyses

Basic descriptive analyses, including frequencies, means, and dispersions, were calculated to describe the study population. To some extent missing values exist in the survey due to both skipped items and inclusion of partial completed questionnaires, resulting in a variable number of observations in the analyses performed. For that reason, the total sample size (n) is always specified. In the analyses of differences between responders and non-responders of the survey, the respondent group was defined as parental responses with at least one usable answer. Register data for the actual parental responder were used in these analyses. Given that the mothers completed the majority of the questionnaires, register data on the mother were used when parents shared the completion of the questionnaire, or when another family member had completed the questionnaire. For comparisons, χ^2 tests were used and each supplemented with a Cramer's *V* post-test to assess the magnitude of effect size. Thresholds stated by Cohen (1988) was applied for interpretation of Cramer's *V*. Independent *t*-tests were conducted for comparisons of age between responders and non-responders. Significance level was set at 0.05, and the statistical analyses were conducted using the statistical packages IBM SPSS Statistics version 24 (IBM Corp., 2016) and STATA version 14.2 (StataCorp., 2015).

Results

Questionnaire responses

In total, 1734 parents, corresponding to a response rate of 30.8% (n = 1734/5631), and 933 individuals with ASD, corresponding to a response rate of 16.6% (n = 933/5631), returned the questionnaire. Substantial overlap between parental responses and responses from the adolescents/adults with ASD was found as there were responses from both parents and adolescents/adults with ASD in 786 cases. The parental questionnaire was completed by both parents in 13.9% of the cases (n = 239/1724), by the mother only in 77.3% of the cases (n = 1332/1724), by the father only in 8.7% of the cases (n = 150/1724) and others (including other family members) in 0.2% of the cases (n = 3/1724). In the questionnaires completed by the

adolescents/adults with ASD, 26.9% (n = 230/855) indicated that they had assistance in completing the survey.
With respect to the individuals with ASD and their parents choosing not to respond to the questionnaires, a smaller subgroup of these non-responders, primarily parents, gave reasons for not completing the survey via telephone or e-mail. These included for example that the ASD diagnosis was later re-evaluated and not confirmed, or the parents felt confident that the ASD diagnosis was not valid; some parents found the questionnaire comprehensive or too difficult; and some adolescents/adults with ASD wanted no further confrontation with the diagnosis.

Comparisons between responders and non-responders
A comparison of different characteristics of the individuals with ASD between responders and non-responders using χ^2 tests is provided in Table 2.
[insert Table 2]
No significant difference was found when comparing the sex of the individuals with ASD in the respondent group and the non-respondent group (χ^2 (1, N = 5631) = 0.02, p = 0.90, V = 0.0016). When comparing the ASD diagnoses registered in the DPCRR in the individuals eligible for the study, a significant different distribution of diagnoses was seen between the respondent group and the non-respondent group, with a small effect size (χ^2 (4, N = 5631) = 15.01, p < 0.01, V = 0.0516), with a slightly higher proportion of individuals registered with the diagnosis of Asperger's syndrome among responders (39.7%) compared with non-responders (34.7%). We also investigated whether responders more often than non-responders were later referred to child psychiatric hospitals. For this analysis, the responders and non-responders were divided into three subgroups: 1) individuals with no further psychiatric hospital visits after receiving the ASD diagnosis; 2) individuals with further psychiatric hospital visits where an ASD diagnosis was maintained in the medical record; and 3) individuals with further psychiatric hospital visits but where an ASD diagnosis was not maintained in the medical record. No significant difference was found between responders and non-responders in this analysis (χ^2 (2, N = 5631) = 1.06, p = 0.59, V = 0.0137). Moreover, the proportion of individuals with ASD without psychiatric hospital visits and with (at least one) psychiatric hospital visit(s) prior to the psychiatric assessment resulting in the first ASD diagnosis was compared. Significantly fewer responders (18.7%) compared with non-responders (21.3%) had at least one psychiatric hospital visit before the ASD diagnosis was applied, a finding with a below-small effect size (χ^2 (1, N = 5631) = 5.00, p = 0.03, V = 0.0298). No significant difference was found with regard to mean age at diagnosis of ASD between responders (9.2 ± 3.2 years) and non-responders (9.2 ± 3.2 years; t = –0.22, p = 0.83) whereas current mean age of the individuals with ASD differed significantly between responders (20.7 ± 2.7 years) and non-responders (20.3 ± 2.7 years; t = –4.70, p < 0.01) with a difference in mean age of 4–5 months.
Comparison of sociodemographic data on the parents of responders and non-responders using χ^2 tests is provided in Table 3.
[insert Table 3]
A statistically significant difference with a small effect size was found in those with the highest completed parental education (χ^2 (3, N = 5631) = 109.20, p < 0.01, V = 0.1393). For example, the proportion of responding parents with a postsecondary education (81.8%) was higher than the proportion among non-responders (70.5%). Likewise, a comparison of the main occupation of the individual parent as well as

the parental household according to income showed significant differences with small effect sizes between responders and non-responders. In both analyses, the proportions of responders in the labor market were higher (individual: 82.8%; household: 90.1%) than the proportions of non-responders (individual: 72.9%; household: 81.6%). Current parental place of living according to geographical regions in Denmark revealed a significant difference with a small effect size between responders and non-responders (χ^2 (4, N = 5631) = 14.19, $p < 0.01$, V = 0.0502), with more non-responders, particularly in the capital region (37.5% vs. 33.6%). No significant difference was found between responders and non-responders regarding current parental place of living according to population density (χ^2 (5, N = 5631) = 7.64, p = 0.18, V = 0.0368), whereas a significant difference in mean age of around 1.5 years was found (t = –10.27, $p < 0.01$) for parental age of responders (51.1 ± 5.4 years) and non-responders (49.5 ± 5.4 years).

Description of study population

For the study population, the proportions of adolescents and young adults with different ASD diagnoses are presented in Table 4 for the total and sex-stratified sample, and in Table 5 for subgroups according to age of diagnosis of ASD. The percentage of individuals with Asperger's syndrome was 42.0% of the total sample, followed by infantile autism (29.2%), other PDD (11.8%), and atypical autism (11.2%). In the subgroup diagnosed with ASD prior to the age of 7 years the proportion of individuals with infantile autism was by far the largest (49.2%), followed by Asperger's syndrome (25.1%). A sex difference was seen in the total population where the proportion of females diagnosed with Asperger's syndrome was lower than males (34.5% vs. 43.8%), and the proportions of atypical autism and other PDD were higher among females than among males (atypical autism: 14.6% vs. 10.4%; other PDD 15.3% vs. 11.0%).

[insert Table 4-5]

ID was seen in 16.7% of the study population (15.6% of males and 21.7% of females; Table 4). The subgroup diagnosed with ASD before 7 years of age had a higher rate of ID of 28.9% (Table 5). In total, 7.3% of the study population was reported by parents to currently have no age-appropriate language, including no language at all, and epilepsy was identified in 3.3% of the sample (Table 4).

It was found that approximately 43.7% of the study population with ASD had current comorbid psychiatric conditions, with the highest frequencies seen for attention deficit hyperactivity disorder (ADHD)/attention deficit disorder (ADD) (19.2%), anxiety (9.7%), depression (8.7%), obsessive compulsive disorder (OCD) (5.7%), and learning disabilities (5.4%) (Table 4). The proportion of males with no current psychiatric comorbidity was higher than in females (58.1% vs. 48.7%). Additionally, more males with ASD had learning disabilities and Tourette's syndrome than females, whereas females were more often affected by, in particular, anxiety, depression and OCD than males (Table 4). In addition to the diagnosis of ASD, 26.5% (n = 380/1434) of the study sample had one comorbid psychiatric diagnosis, 9.3% (n = 134/1434) had two psychiatric diagnoses, and 4.3% (61/1434) had three or more psychiatric diagnoses.

With regard to current availability of services and support for the individual with ASD and/or the family, 34.7 % (n = 500/1443) reported that the support/services received were always or sometimes adequate, 39.7% (n = 573/1443) reported that the support/services received were inadequate, and 25.6% (n = 370/1443) reported that there was no need for support/services.

Discussion

This paper describes the study population of a Danish nationwide survey of children diagnosed with ASD, who at present are 16–26 years of age. Additionally, a thorough comparison between survey responders and non-responders was performed with the aim of evaluating the representativeness of the study sample. Comparing the overall response rate of 30.8% seen in this survey with other studies based on surveys involving individuals with ASD and their families are difficult as response rate(s) are only seldom reported in other studies (Crane, Chester, Goddard, Henry, & Hill, 2016; Jones, Goddard, Hill, Henry, & Crane, 2014; Khanna, Jariwala, & West-Strum, 2015; Parsons, 2015). Nevertheless, for surveys involving parents of children with ASD, response rates of 28–29% have been reported (Kalb, Cohen, Lehmann, & Law, 2012; Kamio et al., 2013). These reported response rates are much alike the response rate found in the AutCome study.

Only minor differences were found between responders and non-responders, when investigating whether questionnaire responders were representative of individuals in the Danish population registered with a childhood diagnosis of ASD in DPCRR. When significant differences were found, it was in combination with small or below-small effect sizes. For example, for parental educational level we found a minor tendency for responders to be higher educated compared to non-responders, however, the effect size was small, and the majority of the non-responders (70%) also had higher educations, i.e., the proportions for each category were quite similar for responders and non-responders respectively. Yet, these findings are in line with other studies showing that socioeconomically advantaged families more often participate in research (Egilson, Ólafsdóttir, Leósdóttir, & Saemundsen, 2017; Rodriguez, Tuvemo, & Hansson, 2006), and should be taken into account when interpreting the results from future analyses that will be performed using data from the AutCome study. However, the overall high degree of similarities between responders and non-responders on a considerable number of different variables as mentioned in the results section indicates a high degree of representativeness of the study sample, which together with the large sample size is essential for identifying different aspects of the heterogeneity found among individuals with ASD.

It should be noticed that a discrepancy appeared between parent-reported ASD diagnoses of their child and the registered ASD diagnoses in the DPCRR with slightly more individuals in the category of Asperger's syndrome and fewer individuals in the categories of atypical autism and other PDD in parental reports (comparison of results in Tables 2 and 4). This discrepancy may be due to difficulties among the parents in remembering the exact autism diagnosis, but it may also be the case that parents found it more desirable for their child to be diagnosed with Asperger syndrome than other autism diagnoses, and therefore a tendency towards more parents reporting an Asperger diagnosis is seen. Another explanation could be that a small group of individuals within the study population had a diagnostic re-evaluation of the first-assessed ASD diagnosis, which is not unlikely as the large majority of the study population was in psychiatric care at least once after the psychiatric assessment resulting in the first ASD diagnosis (Table 2).

A lower rate of epilepsy was found in the AutCome study than in other studies, where lifetime prevalence varied between 11% and 39% (Howlin & Moss, 2012). However, a difference in case ascertainment - where only more severe cases of

ASD were diagnosed previously - probably to some extent contributed to the difference (Kaboski et al., 2017). Furthermore, we found a rate of ID of 16.7% in the study population, which is considerably lower than that found in previous follow-up studies of ASD, where reports of half of the samples or more with ID based on assessment of intelligence in adulthood were seen (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996; Billstedt et al., 2011; Eaves & Ho, 2008; Gray et al., 2014; Ruble & Dalrymple, 1996). However, some recent studies indicate that the proportion of individuals with ASD and co-occurring ID are smaller than previously found. A Swedish epidemiological study of children and adolescents 0-17 years of age found that 23.6% of the study population with ASD also had ID (total n=10,025) (Xie et al., 2017), and a British epidemiological study of adults with ASD found a prevalence rate of 1.0% for adults with ASD without ID, which increased to only 1.1% when adults with ASD and ID were included (Brugha et al., 2016). These studies indicate that the rate of individuals with ASD and co-occurring ID might be lower than previously thought. Yet, this issue requires further investigation. Interestingly, but not surprisingly, the rate of ID in the present study was higher in the subgroup diagnosed with ASD before 7 years of age, affecting almost one-third of this group. This subgroup is, to a higher extent, diagnosed with infantile autism which also includes a group of low-functioning children leading to earlier diagnosing. However, the proportion of ID in this subgroup (28.9%) did not differ from the results reported by The Autism and Developmental Disabilities Monitoring Network in the USA where the percentage of 8-year old children with ASD and with co-occurring ID varied from 20%-50% across nine states (Christensen et al., 2016). This indicates that the low rates of ID found in the AutCome study are in line with the more recent studies reporting ID rates in individuals with ASD where more higher functioning cases with ASD are included.

Less than 10% of our study sample had language difficulties, which is substantially lower than seen in other studies, where around 20–30% of the samples have considerable language difficulties in adolescence and adulthood with no vocalization or no meaningful language at all (Levy & Perry, 2011). The high number of participants with Asperger's syndrome could explain, in part, the higher language functioning in our sample. However, it should also be taken into account that the results regarding ID and language level are based on parental reports and not psychological testing done by professionals, which could reveal difficulties not spotted or known by parents.

With regard to psychiatric comorbidity, approximately 43.7% of our study population had at least one other current diagnosis. A substantial variation in rates of psychiatric comorbidity ranging from 4% to 84% is seen in other follow-up studies, as summarized by two reviews (Howlin & Moss, 2012; Levy & Perry, 2011). Yet, the rate of comorbidity in the present study was lower than findings from other population-based samples: 72.5% when assessing lifetime prevalence in adolescents/young adults (Abdallah et al., 2011), 70.8% when assessing 3-month prevalence in children and adolescents (Simonoff et al., 2008), and 54% when assessing current comorbidity in adults with Asperger's syndrome (Gillberg, Helles, Billstedt, & Gillberg, 2016). Furthermore, three follow-up ASD studies using parental reports in data collection, as in the present study, found similar rates of individuals with psychiatric difficulties (52.2%, 77% and 59%, respectively) (Bishop-Fitzpatrick et al., 2016; Eaves & Ho, 2008; Farley et al., 2009). One explanation for the variation in comorbidity rates found is methodological

differences between studies of ASD with respect to ascertainment method and population studied (e.g., clinical or population-based), time of measurement of comorbidity (e.g., current only, lifetime), and methods applied to assess comorbidity (e.g., parental report, diagnostic assessment). For this study, in particular, the combination of the use of a population-based sample instead of a clinical sample and the use of parental reports instead of diagnostic assessment might account for the lower rate. With respect to the frequency of specific psychiatric diagnoses, the most frequently reported in this study is ADHD/ADD, affecting about one-fifth of the study population. Where some studies found similar rates of ADHD (Abdallah et al., 2011; Marriage, Wolverton, & Marriage, 2009), other studies reported even higher rates (Joshi et al., 2013; Simonoff et al., 2008). Other frequent psychiatric diagnoses reported in the present study are anxiety, depression and OCD, however, with lower rates than seen in other studies (Howlin & Moss, 2012; Wigham, Barton, Parr, & Rodgers, 2017). In conclusion, the overall rate of psychiatric comorbidity found in the present study was generally low, however, with the same pattern of the most frequent diagnoses as found in other studies. Furthermore, the higher rates of, in particular, ADHD, depression and anxiety in this study population could indicate a need for assessment and treatment of these psychiatric disorders in adolescents and adults with ASD.

The male predominance seen in the present study is in line with findings from other ASD samples (Christensen et al., 2016; Jensen, Steinhausen, & Lauritsen, 2014; Saemundsen, Magnusson, Georgsdottir, Egilsson, & Rafnsson, 2013), where females seem to be diagnosed with Asperger's syndrome to a lesser extent and more often with other PDD and atypical autism. This may, in part, be explained by a sex difference in expression of ASD symptoms, where females with ASD, for example, express repetitive and stereotypical behavior and restricted interests with less oddness than males with ASD (Beggiato et al., 2016; Kreiser & White, 2014). When it comes to psychiatric comorbidity, our results indicate that females have higher rates of, in particular, anxiety and depression than males, and an overall higher rate of psychiatric comorbidity. This finding is partly supported by Lever and Geurts (2016), who found that adult females with ASD, as seen in the general population, were more likely to receive a diagnosis of depression than males. In addition, a study by Wilson et al. (2016) found slightly higher rates of overall psychiatric comorbidity among females with ASD (61.2%) compared with males (57.6%).

As mentioned above, this study population is less affected by epilepsy, ID, language difficulties, and psychiatric comorbidity than seen in other ASD populations. This may be due to a cohort effect as this study population is diagnosed with ASD in a period where expansion of the autism spectrum has occurred, including not only the severely affected individuals with impaired intellectual and adaptive functioning. Furthermore and very importantly, sampling bias may be less of a problem in this study owing to the study design, as we had the possibility of inviting an entire Danish cohort of individuals born in the 1990s and diagnosed with ASD before the age of 14 years. However, it cannot be precluded whether parents to adolescents or adults with psychiatric comorbidity and other disabilities in addition to the diagnosis of ASD were less likely to complete the survey due to more caregiving duties. To our knowledge no follow-up studies using a similar defined sample exist at the moment but would, however, be important for future comparison. Nevertheless, about three quarters of the adolescents and young adults with ASD and/or their families had a current need for support and services,

even though the reported rates of disabilities and comorbid psychiatric diagnoses were relatively low. This indicates that the diagnosis of ASD still has a major impact on the majority of the study population.

This study, which is among the largest ASD follow-up studies to date, has several strengths. The large sample size allows for diversity among individuals with ASD to be revealed, and the large dataset facilitates a range of different analyses on outcome. Additionally and very importantly is the sufficient representativeness of the sample. However, limitations to the study exist. The data in this study were collected via parental reports with no possibility of validating the information given. Nevertheless, parents of children with ASD are usually very involved in the lives of their children, which continues into adolescence and adulthood, presumably resulting in valid information about their children. Additionally, a higher response rate would have strengthened the results and conclusions derived from the survey. However, the comparison between responders and non-responders did not show any considerable differences between the two groups, making it less likely that a higher response rate would change the results and conclusions from studies based on the survey data. With respect to the validity of the ASD diagnoses used, a register-based validation study of diagnosed ASD cases in the DPCRR, primarily of the ICD-10 diagnosis of infantile autism, has formerly been conducted, which included a subgroup constituting 8.7% (n = 538/6218) of the total cohort traced with the purpose to take part in the present study. The medical records of these cases have been reviewed and the diagnosis of infantile autism registered in DPCRR was confirmed in 94% of cases (Lauritsen et al., 2010). It would have been beneficial to re-evaluate the prior and current ASD diagnosis of all included cases in this study, but owing to the sample size, it would have required extensive resources.

In conclusion, the study sample of adolescents and adults diagnosed with ASD in childhood seems to a lesser extent, as previously found in other ASD samples to suffer from comorbid psychiatric diagnoses and other conditions. However, the majority of the sample and/or their families still need support and services. Additionally, the study sample investigated is assumed to be a representative coverage of individuals in Denmark with ASD diagnosed in childhood. Future analyses of this large study population will concentrate on outcome focusing on topics such as adaptive functioning, QoL, and occupation. In addition, investigations of factors associated with different outcomes will be performed. Such topics are of foremost importance when studying outcome in populations with ASD.

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Table 1 Information on register data used in the study

Description of register (Danish abbreviation of register name)	**Year**	**Population**	**Register variable(s)** (variable description)	**Eventual grouping of variable** (variable codes)
Psychiatric events from DPCRR (via LPR)	2014			
		ASD	c_diag* c_tildiag* c_adiag*	ICD-10 diagnostic code for (first) ASD (F84)**
		ASD	Date and year of (first) ASD diagnosis	
		ASD	d_inddto and d_uddto	Psychiatric care/visit: A period between date of admission and date of discharge at a psychiatric department (both inpatient and outpatient care)
Highest completed education (UDDF)	2014	Parents	HFAUDD converted to H1 codes (highest completed education)	No education (none of the codes listed below) Primary and lower secondary education (10) Upper secondary education (20, 25) Postsecondary education and qualifying vocational education (35, 40, 50, 60, 65, 70)
Family income (FAIK)	2013	Parents	FAMSOCIOGRUP_13 (main occupation according to income, household)	At the labor market (110-114, 120, 131-135, 139) Not at the labor market: Unemployed, on sick pay, benefit from leave of absence (210, 220) Not in the labor force I: Disability pension, social security benefit (321, 330) Not in the labor force II: Retirement pension, early retirement, enrolled in education (310, 322, 323)
Relation to the labor market (AKM)	2013	Parents	SOCIO13 (main occupation according to income, individual)	At the labor market (110-114, 120, 131-135, 139) Not at the labor market: Unemployed, on sick pay, benefit from leave of absence (210, 220) Not in the labor force I: Disability pension, social security benefit (321, 330) Not in the labor force II: Retirement pension, early retirement, enrolled in education (310, 322, 323)
Information on the population (BEF)	2014			
		Parents	KOM (municipalities)	1) Municipalities grouped into Danish regions:*** Capital Central part of Jutland Northern part of Jutland Zealand Southern part of Denmark 2) Municipalities grouped into density of population:**** Densely populated Intermediate populated, town with ≥40,000 inhabitants Intermediate populated, town with < 40,000 inhabitants Intermediate populated, town with < 15,000 inhabitants Thinly populated, town with ≥ 15,000 inhabitants Thinly populated, town with < 15,000 inhabitants
		ASD	Gender	
		Parents and ASD	Date and year of birth	

DPCRR: Danish Psychiatric Central Research Registry; ASD: autism spectrum disorder
*ASD diagnoses from assessments at the emergency ward were excluded. **F84.2-F84.4 and F84.9 were excluded. ***Grouped according to official Danish geographical regional boundaries ****Grouped via DEGURBA: Degree of Urbanization
Analyses using data from DPCRR concerning ASD diagnosis and psychiatric care were conducted by Statistics Denmark

Table 2 Comparisons between responders and non-responders of the survey I: Data on individuals with autism spectrum disorder (ASD)

Variables	Responders n (%)	Non-responders n (%)	χ^2	df	*p*-value	Cramer's *V*
Gender						
Male	1409 (81.3)	3172 (81.4)				
Female	325 (18.7)	725 (18.6)				
			0.02	1	0.902	0.0016
ASD diagnosis						
Infantile autism	508 (29.3)	1177 (30.2)				
Atypical autism	225 (13.0)	550 (14.1)				
Asperger's syndrome	688 (39.7)	1354 (34.7)				
Other PDD	290 (16.7)	745 (19.1)				
Not classified	23 (1.3)	71 (1.8)				
			15.01	4	0.005	0.0516
Psychiatric care after ASD diagnosis						
No hospital visits	85 (4.9)	194 (5.0)				
Hospital visit(s); ASD diagnosis maintained	1641 (94.6)	3676 (94.3)				
Hospital visit(s); ASD diagnosis not maintained	8 (0.5)	27 (0.7)				
			1.06	2	0.588	0.0137
Psychiatric care before ASD diagnosis						
No hospital visits before ASD diagnosis	1409 (81.3)	3065 (78.7)				
Hospital visit(s) before the ASD diagnosis	325 (18.7)	832 (21.3)				
			5.00	1	0.025	0.0298

Other PDD: other pervasive developmental disorder; df: degrees of freedom
Interpretation of Cramer's *V* (small; medium; large): for df =1 (0.10; 0.30; 0.50), for df=2 (0.071; 0.212; 0.354), for df=3 (0.058; 0.173; 0.289), for df=4 (0.050; 0.150; 0.250), for df=5 (0.045; 0.134; 0.224)

Table 3 Comparisons between responders and non-responders of the survey II: Parental sociodemographic data

Variables	Responders n (%)	Non-responders n (%)	χ^2	df	*p*-value	Cramer's *V*
Highest completed education						
No education	42 (2.4)	266 (6.8)				
Primary and lower secondary education	173 (10.0)	683 (17.5)				
Upper secondary education	100 (5.8)	199 (5.1)				
Post-secondary education, qualifying vocational education	1419 (81.8)	2749 (70.5)				
			109.20	3	<0.001	0.1393
Main occupation according to income: Individual responder						
In the labor market	1436 (82.8)	2842 (72.9)				
Not in the labor market: Unemployed, on sick pay, benefit from leave of absence	47 (2.7)	188 (4.8)				
Not in the labor force I: Disability pension, social security benefit	192 (11.1)	700 (18.0)				
Not in the labor force II: Retirement pension, early retirement, enrolled in education	27 (1.6)	63 (1.6)				
Not classified	32 (1.9)	104 (2.7)				
			67.64	4	<0.001	0.1096
Main occupation according to income: Household of responder						
In the labor market	1563 (90.1)	3178 (81.6)				
Not in the labor market: Unemployed, on sick pay, benefit from leave of absence	22 (1.3)	127 (3.3)				
Not in the labor force I: Disability pension, social security benefit	117 (6.8)	483 (12.4)				
Not in the labor force II: Retirement pension, early retirement, enrolled in education	22 (1.3)	40 (1.0)				
Not classified	10 (0.6)	69 (1.8)				
			77.22	4	<0.001	0.1171
Geographical regions in Denmark: Current residence						
Capital	583 (33.6)	1462 (37.5)				
Central part of Jutland	395 (22.8)	761 (19.5)				
Northern part of Jutland	180 (10.4)	356 (9.1)				
Zealand	279 (16.1)	607 (15.6)				
Southern part of Denmark	297 (17.1)	711 (18.2)				
			14.19	4	0.007	0.0502
Density of population: Current residence						
Densely populated	465 (26.8)	1158 (29.7)				
Intermediate populated, town with ≥ 40,000 inhabitants	232 (13.4)	532 (13.7)				
Intermediate populated, town with < 40,000 inhabitants	412 (23.8)	849 (21.8)				
Intermediate populated, town with < 15,000 inhabitants	50 (2.9)	114 (2.9)				
Thinly populated, town with ≥ 15,000 inhabitants	224 (12.9)	521 (13.4)				
Thinly populated, town with < 15,000 inhabitants	351 (20.2)	723 (18.6)				
			7.64	5	0.177	0.0368

df: degrees of freedom
Interpretation of Cramer's *V* (small; medium; large): for df =1 (0.10; 0.30; 0.50), for df=2 (0.071; 0.212; 0.354), for df=3 (0.058; 0.173; 0.289), for df=4 (0.050; 0.150; 0.250), for df=5 (0.045; 0.134; 0.224)

Table 4 Autism spectrum disorder (ASD) diagnosis, comorbid disorders and conditions in the study population according to parental report

	n (%)	n males (%)	n females (%)
ASD diagnosis			
Infantile autism	435 (29.2)	350 (29.0)	85 (30.2)
Atypical autism	167 (11.2)	126 (10.4)	41 (14.6)
Asperger's syndrome	626 (42.0)	529 (43.8)	97 (34.5)
Other PDD	176 (11.8)	133 (11.0)	43 (15.3)
ASD not classified according to ICD-10	85 (5.7)	70 (5.8)	15 (5.3)
Intellectual disability			
Minimal	58 (4.0)	43 (3.7)	15 (5.6)
Moderate	54 (3.8)	38 (3.3)	16 (6.0)
Severe	29 (2.0)	21 (1.8)	8 (3.0)
Unknown severity	99 (6.9)	80 (6.9)	19 (7.1)
Total	240 (16.7)	182 (15.6)	58 (21.7)
Language development			
Normal or near normal	1369 (92.4)	1110 (92.4)	259 (92.2)
No age-appropriate language use/only speaking sometimes	61 (4.1)	50 (4.2)	11 (3.9)
Nearly no or no vocalization at all	47 (3.2)	38 (3.2)	9 (3.2)
Current psychiatric comorbidity			
ADHD/ADD	275 (19.2)	227 (19.5)	48 (18.0)
Anxiety	139 (9.7)	93 (8.0)	46 (17.2)
Depression	125 (8.7)	88 (7.5)	37 (13.9)
OCD	82 (5.7)	58 (5.0)	24 (9.0)
Learning disabilities	77 (5.4)	69 (5.9)	8 (3.0)
Tourette's syndrome	58 (4.0)	51 (4.4)	7 (2.6)
Eating disorder	27 (1.9)	17 (1.5)	10 (3.7)
Schizophrenia incl. other psychoses	27 (1.9)	24 (2.1)	3 (1.1)
Other disorder*	45 (3.1)	36 (3.1)	9 (3.4)
Unsure (parental reports)	53 (3.7)	45 (3.9)	8 (3.0)
No psychiatric comorbidity	808 (56.3)	678 (58.1)	130 (48.7)
Epilepsy			
Current	49 (3.3)	34 (2.8)	15 (5.4)
Previously only	47 (3.2)	28 (2.3)	19 (6.8)
Blindness or very reduced vision	63 (4.3)	50 (4.2)	13 (4.7)
Deafness or severe hearing impairment	22 (1.5)	19 (1.6)	3 (1.1)
Motor disability	115 (7.9)	88 (7.5)	27 (9.6)

Total n varies between 1434 and 1489

Other PDD: other pervasive developmental disorder; AD(H)D: attention deficit (hyperactivity) disorder; OCD: obsessive compulsive disorder

*This category contains other psychiatric disorders with a small number of participants each disorder

Table 5 Autism spectrum disorder (ASD) diagnoses and intellectual functioning in age groups at diagnosis of ASD

	ASD diagnosed < 7 y n= 497 Mean ± SD age 4.98 ± 1.2	**7 y ≤ ASD diagnosed < 10 y n = 603 Mean ± SD age 9.14 ± 1.1**	**10 y ≤ ASD diagnosed ≤ 14 y n = 634 Mean ± SD age 12.59 ± 0.9**
	n (%)	**n (%)**	**n (%)**
ASD diagnosis			
Infantile autism	210 (49.2)	113 (21.4)	112 (21.0)
Atypical autism	56 (13.1)	48 (9.1)	63 (11.8)
Asperger's syndrome	107 (25.1)	265 (50.2)	254 (47.6)
Other PDD	37 (8.7)	64 (12.1)	75 (14.0)
ASD not classified according to ICD-10	17 (3.9)	38 (7.2)	30 (5.6)
Intellectual disability			
Minimal	21 (5.0)	18 (3.6)	19 (3.7)
Moderate	32 (7.7)	13 (2.6)	9 (1.8)
Severe	20 (4.8)	6 (1.2)	3 (0.6)
Unknown severity	48 (11.5)	28 (5.6)	23 (4.5)
Total	121 (28.9)	65 (13.0)	54 (10.5)

Total n for each subgroup varies between 418 and 534
ASD: autism spectrum disorder; Other PDD: other pervasive developmental disorder

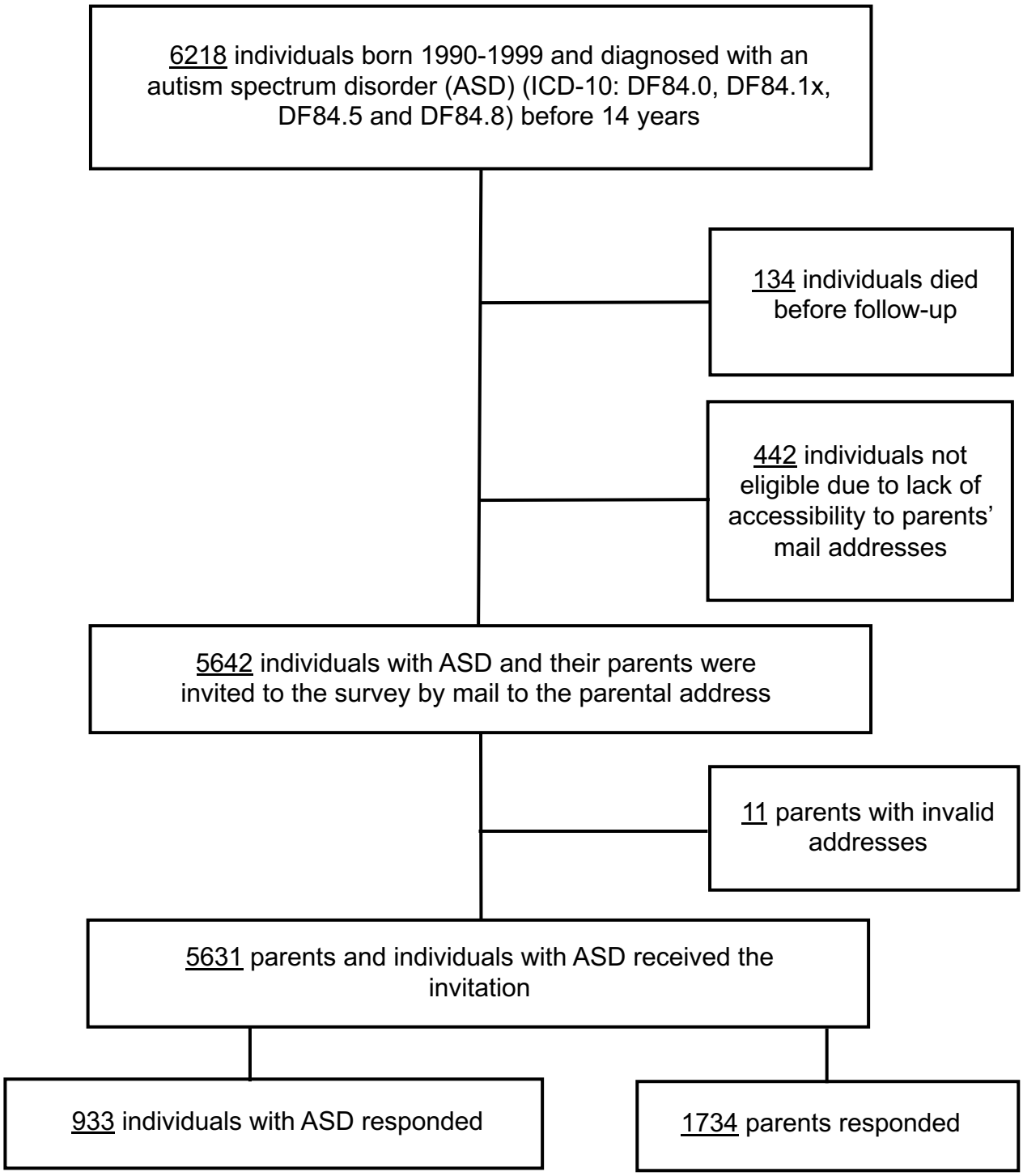

Figure 1 Flowchart depicting the selection of study participants