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Diagnosing autism spectrum disorder among children in Norway

ORIGINAL ARTICLE

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BACKGROUND

The percentage share of children who are diagnosed with autism spectrum disorder has increased considerably since the 1990s in Norway as well as in other countries. It has previously been demonstrated that there is considerable variation between counties with respect to diagnostic practice.

MATERIAL AND METHOD

We calculated the percentage of children with autism spectrum disorder by using patient data obtained from the Norwegian Patient Registry and population data obtained from the National Registry. The calculations were made for the country as a whole as well as by county. The diagnostic assessments and documentation were mapped by linking the Norwegian Patient Registry with the Norwegian Mother, Father and Child Cohort study. We also reviewed patient records obtained from the specialist health service and considered whether diagnostic practice satisfied the research criteria for autism spectrum disorder.

RESULTS

By the age of eight, 1.1 % of boys and 0.3 % of girls had been diagnosed with autism spectrum disorder. The overall percentages varied from 0.3 to 1.0 between counties. From 2008 to 2016, these percentages increased in all age groups. Our review of patient records included 503 children. In 95 % of cases the patient records provided a high standard of documentation that the diagnostic research criteria had been satisfied. The assessments were largely conducted in accordance with the guidelines drawn up by the various health trusts.

INTERPRETATION
Autism diagnoses are generally well documented within the Norwegian specialist health service and meet the diagnostic criteria. In the counties that demonstrate a low prevalence of autism, it appears the health service fails to recognise autism in many children, particularly girls, or the diagnosis is determined late.

Main findings

Data from the Norwegian Patient Registry showed that 1.1 % of boys and 0.3 % of girls had been diagnosed with autism spectrum disorder at the age of eight.

The percentages increased over time in all age groups and in both genders, with considerable variation by county.

In the counties with a low prevalence rate, it may appear that the health service failed to recognise autism in many children, particularly girls, or the diagnosis was determined late.

The number of children who are diagnosed with autism spectrum disorder has increased considerably since the 1990s, in Norway as well as in other high-income countries. Using figures from Norwegian health registries it has been estimated that 0.9 % of children have received the diagnosis by the age of 12 (1). Corresponding figures from Stockholm in Sweden are higher, at 1.7 % in the age group 6–12 years, and 2.5 % in the age group 13–17 years (2). In Denmark, the percentage share of children with autism is 1.5 % at ten years of age (3), and in the USA the share is 1.5 % in eight-year-olds (4).

Autism spectrum disorder (hereafter referred to by its short form, autism) is characterised by three core symptoms: persistent impairment in social interaction, persistent communication difficulties, and repetitive, restricted and stereotyped behaviour (5). The International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) divides autism into subtypes (5). The most commonly used subtype diagnoses are childhood autism, Asperger's syndrome and atypical/unspecified autism. Childhood autism is diagnosed if the child displays all the core symptoms and if onset is before the age of three. Asperger's syndrome is used when the child shows clear impairment in social interaction and has other typical behavioural autism symptoms, but not late development of language or cognition. Atypical / unspecified autism is not clearly defined in the diagnosis manual, but the diagnosis is used for children who show autistic symptoms but do not satisfy the criteria for childhood autism or Asperger's syndrome. In the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5), which is used in clinical practice in the USA and Canada as well as in research on autism, the subtype categories were removed in 2013 (6). The same will happen when ICD-11 is published (7).

In the 1990s, a number of diagnostic instruments were developed for the assessment of autism.

Today their use is considered standard procedure in research as well as in clinical practice. The Autism Diagnostic Interview – Revised (ADI-R) (8) is a parental interview which seeks to identify the symptoms of autism, while the Autism Diagnostic Observation Schedule (ADOS) (9) is an instrument based on interactive play or conversation that seeks to assess the child's social interaction, communication and behaviour.

The regional health trusts have drawn up guidelines for the assessment of autism. They recommend the use of standardised diagnostic instruments (10). It is also a requirement that all assessments include measurements of ability levels, language functions, attention and memory functions, play and creativity as well as adaptive skills (10). Additionally, the guidelines provide detailed standards for the recording of medical histories and undertaking medical assessments (10). The diagnosis must always be determined on the basis of an overall clinical assessment.

Despite the detailed guidelines, the percentage of children who are diagnosed with autism has been found to vary considerably between counties (1). This necessitates an examination of the basis on which the diagnoses are determined. The national prevalence figures should also be updated to establish whether the increase continues.

In this article we present updated figures for the percentage share of children and young people who receive autism diagnoses, for the country as a whole and by county. Furthermore, we present the results of a national study that sought to establish how autism is diagnosed and documented within the specialist health service.

Material and method

National registry data

The Norwegian Patient Registry (hereafter referred to as the Patient Registry) holds identifiable personal data dating back to 2008. This study made use of data from mental healthcare providers for children and young people, somatic hospitals and specialist private consultants from 2008 to 2016 inclusive. Autism was defined as one or several recordings of the diagnosis code F84 (pervasive developmental disorders, which is the term used for autism in ICD-10) (11).

Autism is normally diagnosed from the age of two in Norway. We estimated the percentage of children who had received the diagnosis before the age of eight by means of Kaplan-Meier analyses, for the country as a whole as well as county by county. We included all children born between 2006 and 2014 inclusive, i.e. everyone with follow-up data recorded in the Patient Registry from the

calendar year of their second birthday. Only very few children are diagnosed with autism before the age of two in Norway, so we assume that virtually all autism diagnoses will be included in this group.

At the end of the follow-up period, the population was aged between two and 10, but we chose to end the Kaplan-Meier curves at eight years old because the county estimates were too uncertain for the nine and ten-year-olds. The comparisons between counties were therefore made for the eight-year-old cohort. For the county estimates, we calculated confidence intervals for comparison between the counties and the national average. Because we were conducting multiple comparisons (19 counties), we used confidence intervals of 99.7 % (based on the Bonferroni correction). The analyses were conducted in Stata 15 (StataCorp. 2017).

We also wanted to study any changes in diagnostic practice over time. For each calendar year, we therefore calculated the percentage of children whose entries included an autism diagnosis in the period 2008–16, by gender and age group. These calculations included everyone in the age group 2–17 in the relevant calendar year. Population data were obtained from the National Registry (12).

Review of patient records

The diagnostics study was part of the Autism Birth Cohort Study (the Autism Study) (13), a sub-study of autism in the Norwegian Mother, Father and Child Cohort Study (14). This included 114 500 children and young people born between 1999 and 2009 inclusive. The Autism Study identified children with autism by asking participants in the Mother, Father and Child Cohort Study to complete a questionnaire when the child reached three years of age. Only 62 children with autism were identified through this screening. This was because the questionnaire response rate was lower than expected (59 %), because the sensitivity of the screening was low and because many participants who tested positive, did not wish to travel to Oslo to take part in clinical assessments. Furthermore, we identified 19 children with autism on the basis of the questionnaires at five and seven years of age, which included questions relating to autism and Asperger's syndrome. A further three children with autism were identified in the control group of 368 three-year-olds who took part in the clinical screening (figure 1).

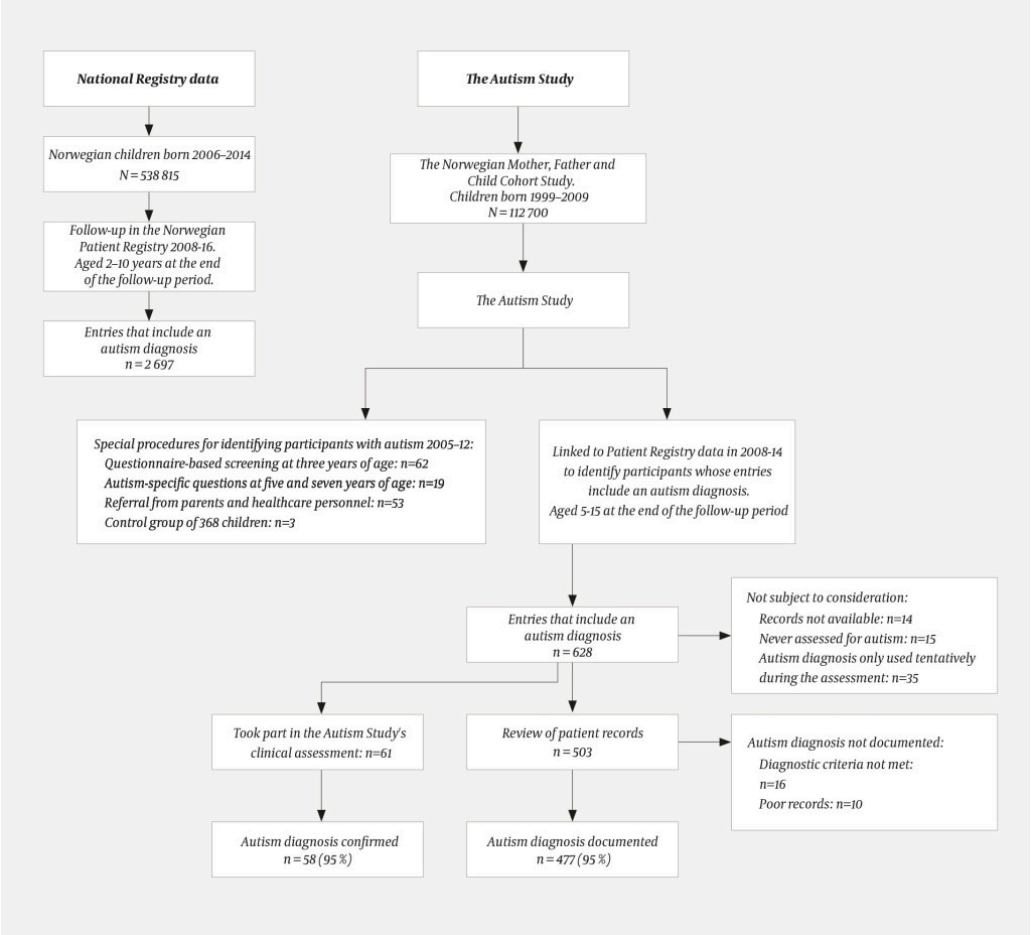

Figure 1 Flow chart for the two study populations

The Autism Study invited parents and healthcare personnel to refer children from the Mother, Father and Child Cohort Study straight to them if autism was suspected. A total of 53 children with autism were identified following these referrals.

We also linked the Mother, Father and Child Cohort Study to the Patient Registry in order to identify all participants who had received an autism diagnosis through the specialist health service. These children were also invited to a clinical screening. Of the 61 children who took part, 58 (95 %) had their autism diagnosis confirmed after the clinical assessment (95 % CI 86–99).

There were 628 participants in the Mother, Father and Child Cohort Study who were recorded in the Patient Registry at the end of 2014 as having an autism diagnosis (figure 1). Of these, 61 had taken part in the Autism Study's clinical screening. This meant that 567 children were candidates for having their patient records reviewed.

The protocol for the review of patient records was developed by three of the co-authors; two of them specialists in clinical psychology (ASØ and SS) and one of them a psychologist (AH). All are certified users of the diagnostic instruments and have experience from the clinical assessments carried out in the Autism Study. The review of patient records was largely conducted by ASØ and AH. At a small number of hospitals, the review was conducted by the hospital's own staff under guidance from ASØ and AH.

During the review of patient records, we mapped the progress from referral to assessment stage, recorded the results of standardised interviews and tests as well as what diagnoses the children had received. Following the review of patient records we considered whether the child met the diagnostic criteria that have been defined for research on autism (11). As a rule, each patient file was reviewed by a single psychologist, but when there was doubt, the medical history and all findings were reviewed by both psychologists and a conclusion drawn by consensus. The protocol is supplied as an appendix.

If the psychologist concluded that the diagnosis had not been documented sufficiently robustly in the records, one of the following reasons would have to be cited: 1) The child did not suffer from autism (did not meet the diagnostic criteria), 2) poor record-keeping, 3) records not available, or 4) incorrect code attributed.

We calculated a positive predictive value of registered autism diagnoses by dividing the number of children who had received a robustly documented autism diagnosis by the total number of children whose records were available.

The Regional Committee for Medical and Health Research Ethics has approved the use and review of registry data as well as the review of patient records (ref. 2010/2583 and 2011/701). The Mother, Father and Child Cohort Study is regulated by Norwegian regulations concerning population-based health studies under the Health Registry Act and the Health Research Act. Participation was based on informed consent from parents and involves obtaining data from health registries and hospital records. A separate letter of information was sent to everyone who was included in the review of patient records.

Results

National registry data

Of 538 815 children born in the period 2006–14, there were 2 697 aged 2–8 years who had been registered with autism on one occasion or more (figure 1). By the time they had reached eight years of age, 1.1 % of boys and 0.3 % of girls had received an autism diagnosis (figure 2). The overall rate of prevalence was 0.7 % and varied between counties, from 0.3 % in Hedmark to 1.0 % in Rogaland (figure 3). Hedmark, Aust-Agder, Vest-Agder and Nordland were significantly below the national average, while Møre og Romsdal and Rogaland were significantly above.

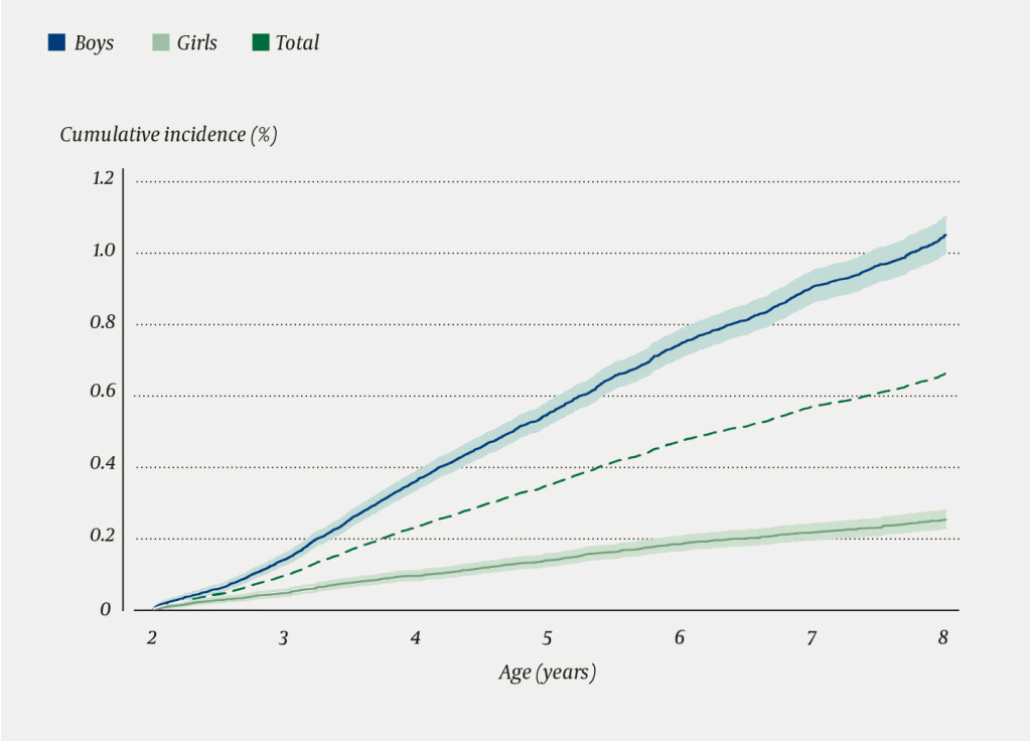

Figure 2 Percentage share of children diagnosed with autism spectrum disorder, by age and gender. Data from the Norwegian Patient Registry and the National Registry 2008–16 that include children born 2006–14 (N = 538 815) registered with an autism diagnosis at between 2 and 8 years of age (cumulative percentages). Gender-specific curves are shown with 99.7 % confidence intervals.

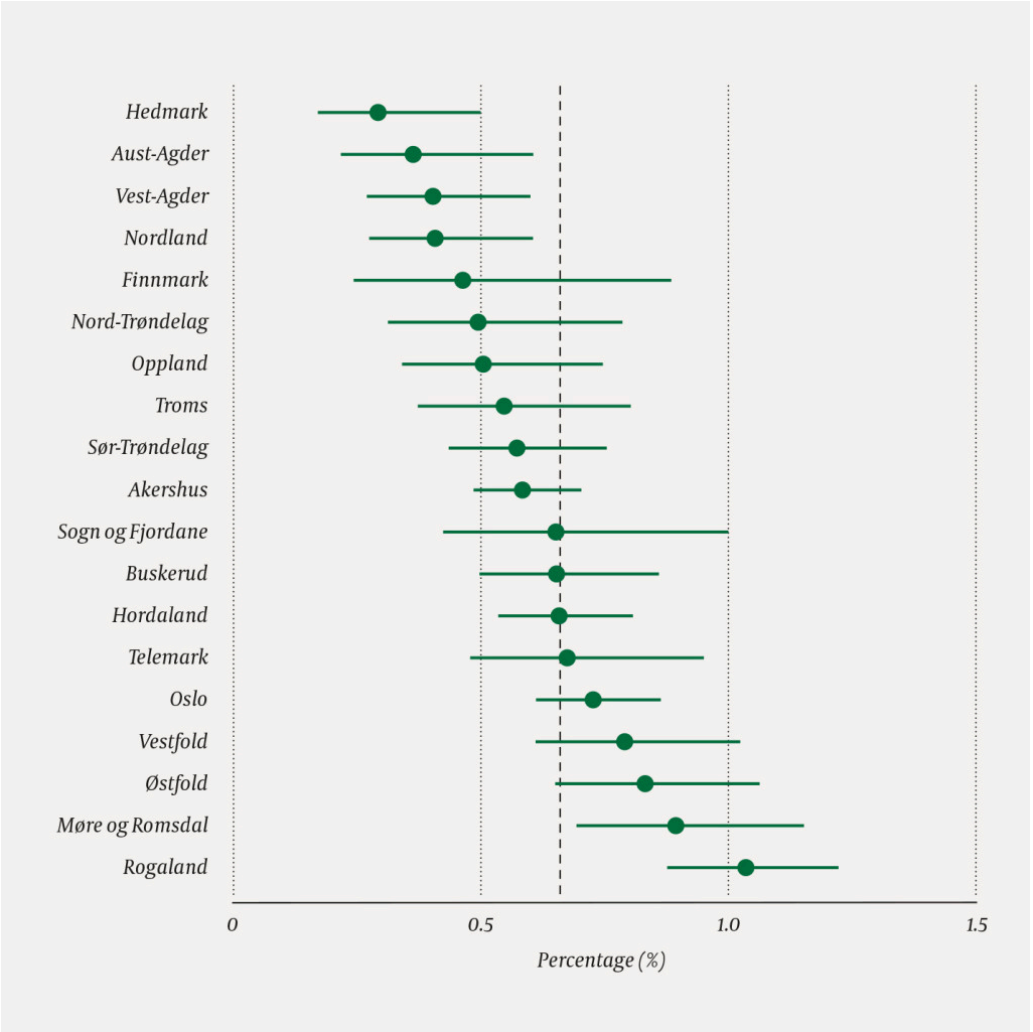

Figure 3 Percentage of children with autism spectrum disorder at the age of eight, by county. Data from the Norwegian Patient Registry and the National Registry 2008–16 that include children born 2006–14 (N = 538 815) registered with an autism diagnosis at the age of 2–8 (cumulative percentages). The vertical line is the national average, horizontal lines are 99.7 % confidence intervals.

For the country as a whole, there were 4.4 times more boys than girls whose registry entry included an autism diagnosis at the age of eight; the variation between counties ranged from 2.4 in Troms to 7.2 in Hordaland. Mean age at the time of the first registration was 4.9 years for Norway as a whole, varying between 4.0 years in Aust-Agder to 5.5 years in Finnmark.

Figure 4 shows the percentage of children whose registry entry includes an autism diagnosis in each of the calendar years in the period 2008–16. The percentage has increased in all age groups for both genders. The county-specific figures have remained stable or rising throughout the period. The exception is Telemark, where the percentage has fallen.

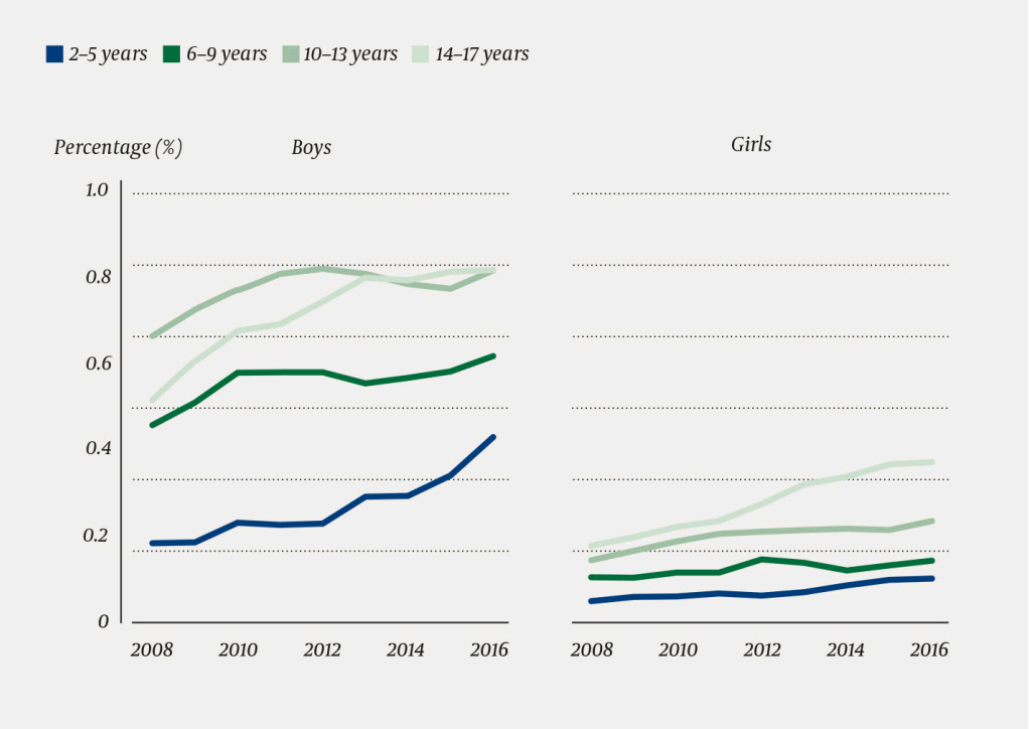

Figure 4 Percentage of children registered with autism spectrum disorder per calendar year. Data from the Norwegian Patient Registry and the National Registry 2008–16.

Review of patient records

Of the 567 children who were relevant candidates for the review of patient records, files were available for 503 (89 %) who had been given an autism diagnosis by a doctor or psychologist (figure 1). Their age at the time of diagnosis varied between one and 13 years, and the median age was seven. The median period between referral and diagnosis was 14 months. A total of 290 children (58 %) had been referred due to social difficulties or other specific concerns about potential autism (table 1). Most of the patient files documented a comprehensive assessment (table 2). A full overview of the assessment instruments is given in table 3.

Table 1

Charting of autism diagnoses following our review of patient records for children with autism spectrum disorder (N = 503).

	No.	Percentage
Gender		
Boy	423	84
Girl	80	16
Reason for referral		
Social difficulties/suspected autism	290	58
Late development (general lateness, late development of language and/or learning difficulties)	129	26
Other specified mental disorder suspected	232	46
Other concern or problem	102	20
No information about reason for referral	14	3
Autism diagnosis		
F84.0 Childhood autism	134	27
F84.1 Atypical autism	72	14
F84.2 Rett syndrome	4	1
F84.3 Childhood disintegrative disorder	2	~0
F84.4 Overactive disorder associated with mental retardation and stereotyped movements	1	~0
F84.5 Asperger's syndrome	203	40
F84.8 Other specified pervasive developmental disorder	3	1
F84.9 Unspecified pervasive developmental disorder	84	17
Other diagnoses		
Intellectual disability	62	12
Epilepsy	30	6
ADHD	136	27
Behavioural disorder	27	5
Anxiety	17	3
Obsessive-compulsive disorder	5	1
Sleeping disorder	35	7
Eating disorder	19	4

[1]The total exceeds 100 % because there were several reasons for referral specified for many children.

Table 2

Various assessment components that contributed to a diagnosis of autism spectrum disorder in children (N = 503)

Component	No.	Percentage
Developmental and medical history	432	86
Medical/neurological examination	370	74
Autism-specific screening instrument	175	35
Autism-specific diagnostic interview (Autism Diagnostic Interview – Revised)	359	71
Autism-specific assessment (Autism Diagnostic Observation Schedule, ADOS)	410	82
Ability testing	449	89
Developmental test	66	13
Language test	167	33
Neuropsychological examination	68	14
General assessment of symptoms and functioning: Child Behavior Checklist (CBCL)	156	31
Assessment of hyperactivity and attention difficulties	127	25
Asessment of adaptive functioning	147	29
Direct observation of the child (in school, nursery, clinic etc.)	417	83

Table 3

Full overview of assessment components (N = 503). Some children underwent several interviews/tests/surveys in the same category. The sum total of the numbers quoted for each component is therefore frequently higher than the total number of children who underwent interviews/tests/surveys.

	No.	Percentage
Developmental and medical history	432	86
Medical/neurological examination	370	74
Autism-specific screening instrument	175	35
Autism Spectrum Screening Questionnaire (ASSQ)	83	17
Social Responsiveness Scale (SRS)	45	9
Asperger Diagnostic Interview (ASDI)	20	4

	No.	Percentage
Social Communication Questionnaire (SCQ)	19	4
Children's Communication Checklist 2 (CCC-2)	35	7
Other specified screening instrument	32	6
Autism-specific diagnostic interview	359	71
Autism Diagnostic Interview – Revised (ADI-R)	344	68
Diagnostic Interview for Social and Communication Disorders (DISCO)	17	3
Autism-specific examination: Autism Diagnostic Observation Schedule (ADOS)	410	82
Ability test	449	89
Wechsler Preschool and Primary Scale of Intelligence (WPPSI)	99	20
Wechsler Intelligence Scale for Children (WISC)	236	47
Wechsler Abbreviated Scale of Intelligence (WASI)	6	1
Stanford-Binet Intelligence Scales	16	3
Leiter International Performance Scale – Revised	22	4
McCarthy Scales of Children's Abilities	1	~0
Other specified ability test	5	1
Ability testing documented, type not specified	64	13
Developmental test	66	13
Bayley Scales of Infant Development	39	8
Mullen Scales of Early Learning	3	1
Psychoeducational Profile (PEP)	19	4
Other specified developmental test	5	1
Language test	167	33
Language 6–16	19	4
Reynell Developmental Language Scale	46	9
Illinois Test of Psycholinguistic Abilities (ITPA)	14	3
Peabody Picture Vocabulary Test (PPVT)	6	1
British Picture Vocabulary Test (BPVS)	7	1
Test of Receptive Grammar (TROG)	7	1
Children's Communication Checklist 2 (CCC2)	31	6
Clinical Evaluation of Language Fundamentals (CELF)	3	1
Other specified language test	25	5
Language testing documented, type not specified	9	2
Neuropsychological examination	68	14

	No.	Percentage
General screening for symptoms and levels of functioning: Child Behavior Checklist (CBCL)	156	31
Assessment for hyperactivity or attention disorders	127	25
Barkley ADHD Rating Scale	60	12
Conner's Scale for Assessing ADHD	8	2
Brown ADD Scale	9	2
Quantitative Behavior Test (QB Test) (ADHD-specific test)	31	6
Conner's Continuous Performance Test (CPT) (ADHD-specific test)	6	1
Other ADHD-specific test	13	3
Adaptive skills testing	147	29
Vineland Adaptive Behavior Scales	127	25
Adaptive Behavior Assessment System – II (ABAS-2)	6	1
Other specific screening of adaptive skills	15	3
Direct observation of the child	417	83
School or nursery observation	371	74
Observation in a clinic	289	57
Other type of observation	25	5
Hospitalisation	25	5

For the 503 children who had been positively diagnosed with autism by a doctor or a psychologist, we found that 477 (95 %) of diagnoses were robustly documented in the patient records. The positive predictive value of a recorded autism diagnosis (the number of documented diagnoses divided by the total number of available patient files) was 477/553 = 86 % (95 % CI 83–89).

Discussion

Data from the Patient Registry showed that 1.1 % of boys and 0.3 % of girls had received an autism diagnosis by the time they were eight years old. We found an increase in the use of the diagnosis in all age groups that were included in our study. It is therefore probable that a considerably higher number of children will receive an autism diagnosis before they turn 18.

The findings of our review of patient records suggest that the autism diagnosis is being used in accordance with research diagnostic criteria in Norway. When a doctor or psychologist had determined the diagnosis, the records of 95 % of cases documented that the children met the diagnostic criteria for autism (11). The findings contrast with a similar study of hyperkinetic disorder, where we

found that only 49 % of diagnoses were robustly documented in the records (15). We believe that the high standard of documentation of autism diagnoses is thanks to an extensive use of standardised diagnostic instruments, as recommended (10).

Most of the autism assessments included ability testing and direct observation of the child (10). However, only a minority of the children had been assessed for language and adaptive skills. It is important that these functions are assessed in everyone, because the autism diagnosis indicates difficulties with communication and social interaction, but says nothing about impairments in other areas. In DSM-5 and ICD-11, a description of speech, levels of ability and adaptive skills must be included in the diagnosis (6, 7).

Our study has several limitations. A review of patient records is not an independent validation of a diagnosis, as we have not examined the children ourselves. However, the findings from our review of patient records coincide with the validation of autism diagnoses undertaken in the Autism Study, which confirmed the diagnosis in 95 % of cases. The review of patient records covered too few participants in each county for us to analyse possible causes of the variation, such as access to staff and resources, and socio-economic factors such as income, education and the percentage of immigrants in the resident population. Another limitation was the fact that many records were reviewed by a single psychologist. Ideally, all records should have been reviewed by two medical professionals.

The great majority of autism diagnoses were well documented, which indicates that the autism diagnosis is determined in accordance with the diagnostic criteria even in the counties where a higher proportion of children receive the diagnosis. This suggests that in the counties that demonstrate a low rate of prevalence, the health service fails to recognise autism in some children.

It is well known that autism is more common in boys than in girls. The boy-girl ratio is normally around 4 (16) in clinical practice, whereas screening studies, where all children in a certain cohort are assessed for autism, reveal a ratio of approximately 3 (16). We found that the boy-girl ratio is 4.4, and higher in some counties. This may suggest that some girls with autism remain undiagnosed, or that they are diagnosed at a later stage. This would match the findings of the Children in Bergen study, which showed that girls with developmental or mental problems had a lower probability of being seen by the specialist health service than boys with similar levels of symptoms (17).

In the cases where recorded autism diagnoses had not been documented, this was most commonly due to incorrect coding or because the diagnosis had been set tentatively while the assessment was still on-going. Institutions within the specialist health service must abstain from using F84 codes tentatively before a doctor or psychologist has given a conclusive diagnosis of autism.

Our findings do not exclude the possibility that overdiagnosis of autism may occur in Norway. Use of the diagnosis is increasing in all age groups. Diagnoses are often required in order to trigger assistive measures in the education system, which may contribute to a lowering of the threshold for setting the diagnosis. When figures from Stockholm show that as many as 2.5 % of teenagers have received an autism diagnosis (2), it is a timely question whether

overdiagnosis occurs. It is important to watch how the diagnostic practice develops in Norway and to be on guard against overdiagnosis as well as underdiagnosis of autism.

Conclusion

Autism diagnoses among children are well documented and they are determined in accordance with the diagnostic criteria. However, there is considerable variation between counties with respect to the percentage share of children with the diagnosis. There is reason to believe that in the counties that report the lowest percentages, the health service fails to recognise autism in some children, particularly girls, or the diagnosis is determined late.

The article has been peer reviewed.

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