

## The Early Diagnosis of Preschool Children with Autism Spectrum Disorder in Norway: a Study of Diagnostic Age and Its Associated Factors

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### Abstract

The early identification of autism spectrum disorder is important to ensure access to early intervention. Much research has focused on the identification of early behavioral symptoms and screening. This study examines referral for diagnostic assessment, diagnostic age, and factors associated with diagnostic age for children with autism spectrum disorder. The results of this study indicate that children are referred and diagnosed later than they should be. Previous research has identified a valid time for the identification and diagnosis of this disorder as well as the diagnostic procedures and types of clinics that are associated with the appropriate diagnostic age.

**Keywords:** Diagnostic age; ASD; associated factors

Autism spectrum disorder (ASD) is defined by impairments in social interaction and social communication as well as restricted and repetitive patterns of behavior, interests, and activities. The symptoms are present from early childhood, and they impair or restrict an individual's daily functioning and participation (1,2).

The early identification of ASD is important to reduce parental concern and stress and to secure access to early interventions (3,4). Recent research has had promising results with the implementation of specially designed interventions for infants and toddlers with ASD (5-7). This research has emphasized the importance of identifying and diagnosing children with ASD at an early developmental stage.

Our knowledge of the early symptoms associated with the later diagnosis of ASD has increased through focused research during recent decades. On the basis of this knowledge of early behavioral symptoms related to the core areas of social interaction, social communication, and restricted and repetitive patterns of behavior, interests, and activities, it is generally accepted that children with

ASD may reliably be diagnosed as early as 24 months of age and, for certain children, no later than 36 months of age (4,8-10). However, this may not be the case for all affected children, especially those with less severe symptoms (11).

The actual mean diagnostic age for children with ASD is higher at approximately 48 months of age, and diagnosis sometimes occurs even later (12-15). Relevant studies of diagnostic age are outlined in Table 1. Several factors have been described as affecting the diagnostic age, including symptom severity, regional differences between and within countries (16), level of parent concern, birth order, maternal education, siblings with ASD, development regression, and number of children in the family (17-20). Gender has been proposed as another factor that influences early recognition, but no significant differences between girls and boys have been demonstrated (21). The diagnostic age of children with ASD in Norway is not currently known. Knowledge of the appropriate diagnostic age and factors associated with the actual diagnostic age are important for the development of health care services and for the training of professionals in

**TABLE 1. Relevant Studies of Age at Diagnosis of Autism Spectrum Disorder**

Study	Region	Population (Age Group)	Diagnostic Age (Average in Months) *	Factors Studied
Chakrabarti & Fombonne (2001)	England, Staffordshire	Preschool children	AD AS PDD-NOS Overall	35 52 43 41 Referring source
Magnusson & Saemundsen (2001)	Iceland	5 to 24 years old	AD PDD-NOS	43 to 49† 5†
Mandell et al. (2002)	US, Pennsylvania	3 to 16 years old		76 to 95 Race
Lingam et al. (2003)	England, London		AD AS PDD-NOS	40 97 51
Yeargin-Allsopp et al. (2003)	US, Atlanta	3 to 10 years old		47 Demographic factors, cognitive functioning, source of identification
Daley (2004)	India	2.10 to 27.6 years old		59 Specific symptoms, environmental factors, cultural factors, socioeconomic factors
Keen & Ward (2004)	England, Doncaster	0 to 17 years old		76 Educational placement
Chakrabarti & Fombonne (2005)	England, Staffordshire	Preschool children	AD AS PDD-NOS Overall	33 45 39 38
Juneja et al. (2005)	India, New Delhi	0 to 18 years old	AD	39
Mandell et al. (2005)	US, Pennsylvania	0 to 21 years old	AD AS PDD-NOS	37 86 47 Living area (urban/rural), income, language level, specific symptoms, number of primary care physicians
Goin-Kochel et al. (2006)	Several countries	1.7 to 22.1 years old	AD AS PDD-NOS Overall	41 90 50 54 Number of professionals visited, income
Wiggins et al. (2006)	US, Atlanta	8 years old	AD AS PDD-NOS ASD Overall	59 82 65 53 61 Gender, race/ethnicity, presence of Mental Retardation, degree of impairment
Latif & Williams (2007)	UK, South Wales	0 to 17 years old	AD AS ASD Overall	32 to 43 79 to 86 52 to 78 66 to 71
Oslejskova et al. (2007)	Czech Republic, Brno		AD AS PDD-NOS Overall	74 129 81 82 Diagnostic subgroup
Chen et al. (2008)	Taiwan		AD	45 to 46 Living area
Parner et al. (2008)	Denmark		AD Overall	56 to 61 64 to 71 Cohort
Williams et al. (2008)	England, Avon	0 to 11 years old	AD AS PDD-NOS Overall	45† 116† 76† 8† Gender, maternal educational level
Hertz-Picciotto & Delwiche (2009)	US, California	0 to 9 years old	AD	58 to 63 Cohort
Nassar et al. (2009)	Australia, Western	0 to 8 years old		36 to 48†

Table continues next page

Study	Region	Population (Age Group)	Diagnostic Age (Average in Months) *	Factors Studied	
Ouellette-Kuntz et al. (2009)	Canada, four regions	2 to 18 years old	AD AS PDD-NOS ASD	33 to 44† 89 to 103† 48 to 77† 36 to 47†	Gender, region, year of initial diagnosis, diagnostic subtype
Perryman (2009)	US, North Carolina			46†	
Shattuck et al. (2009)	US		AD ASD Overall	88† 106† 68†	Gender, intelligence quotient, developmental regression, site
Adelman (2010)	US	0 to 11 years old		38	
Mandell et al. (2010)	US	0 to 10 years old	AD ASD Overall	59 to 66 61 to 73 65	
Noterdaeme & Hutzelmeyer-Nickels (2010)	Germany, Munich		AD AS PDD-NOS	76 110 111	
Chamak et al. (2011)	France	4 to 45 years old		20 to 120	
Fountain et al. (2011)	US, California		AD	43 to 60†	
Kalkbrenner et al. (2011)	US, North Carolina	0 to 8 years old		57	
Rosenberg et al. (2011)	US	0 to 18 years old	AD AS PDD-NOS ASD Overall	38 88 45 42 48	
Coo et al. (2012)	Canada	1 to 14 years old	AD AS PDD-NOS ASD Overall	58 94 69 54 61	Diagnostic subgroup, ethnocultural identity, being adopted, neighborhood median household income, urban/rural living area, gender, year of initial diagnosis, birthplace, siblings with ASD
Valicenti-McDermott et al. (2012)	US, University-affiliated developmental center, The Children's Evaluation and Rehabilitation Center (CERC)	1 to 6 years old		38	Ethnicity, maternal education level
Frenette et al. (2013)	Canada, Nova Scotia	0 to 15 years old		55†	
Mishaal et al. (2014)	Israel	15 to 72 months old		28	Gender, first-born status, sibling with ASD, developmental regression, parental age, parental education, Autism Diagnostic Observation Schedule severity score, Autism Diagnostic Interview, Revised, score, Vineland Adaptive Behavior Scales (VABS) composite score
Mazurek et al. (2014)	US, Autism Speaks Autism Treatment Network (AS-ATN)	2.0 to 17.6 years old		64	Cohort effects, parental education, ethnicity, intellectual ability, symptom severity, communications skills, social skills, psychiatric symptoms
Bickel et al. (2015)	US, Boston	Children	ASD, PDD-NOS AS	35 114	Gender, birth order, cognitive functioning, language level, adaptive level, insurance coverage, maternal education, sibling or family member with ASD, number of children in the house
Jo et al. (2015)	US	3 to 17 years old		28 to 76	Ethnicity, symptom severity, family structure, co-occurring health conditions

\*Unless stated otherwise Autism Spectrum Disorders, † Median only

AD, Autistic Disorder; AS, Asperger Syndrome; ASD, autism spectrum disorder; PDD-NOS, pervasive developmental disorder, not otherwise specified; US, United States

primary health care settings and clinics in which children are diagnosed with ASD.

Diagnostic assessment for ASD is a comprehensive interdisciplinary procedure that requires thorough knowledge of both child development and the core areas of ASD. International practice parameters for the assessment and diagnosis of ASD in children have been published (22). In Norway, the Regional Resource Center for Autism, ADHD, Tourette's Syndrome, and Narcolepsy has published regional practice parameters for the assessment and diagnosis of ASD in children, adolescents, and adults (23). These parameters state that diagnostic assessment should include a medical examination; an evaluation of the child's developmental and medical history; and an assessment of the child's social interaction, social communication, language skills, restricted and repetitive behaviors, cognitive level, and adaptive behaviors. It is recommended that most of the assessment should be based on standardized instruments, including the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview, Revised. Whether diagnostic assessment procedures influence the diagnostic age is not known. Different aspects of the diagnostic assessment may influence diagnostic age, including the type of clinic and the use of standardized assessment tools. Research has found that the diagnostic procedures that differ from clinic to clinic can influence diagnostic conclusions (16), especially with regard to subgrouping within the autism spectrum.

Norwegian legislation gives every child who is more than 12 months old the individual right to a place in a day care center. Eighty percent of all children between the ages of 1 and 2 years regularly attend day care centers, and this number rises to 97% for 3- to 5-year-old children. The staff members of day care centers may have bachelor's degrees in childhood education or college degrees in childhood care, or they may have no education beyond mandatory schooling. Norwegian day care centers and preschools focus on play and do not include traditional classroom activities or settings. All Norwegian children have access to health and developmental checks at community health care centers, and they are invited at regular intervals for short follow-up visits. Primary care doctors are free of charge for all children who are 16 years old or younger, and each child has a regular primary care physician. A referral from this doctor or from a community health clinic or child welfare services is required for diagnostic assessment at a specialist clinic.

In accordance with Norwegian law, the diagnostic assessment and official diagnosis of ASD must occur

at a specialized clinic that has been organized at a hospital. Children who are referred to specialist clinics with symptoms of ASD are entitled to health services within a predefined time frame. For children between the ages of 0 and 2 years, health services for ASD assessment should be provided within 4 weeks of recognition of need. The corresponding time frame for children between the ages of 3 and 6 years is 6 weeks. There are two main types of clinics that perform the diagnostic assessment of children with ASD: habilitation clinics and child and adolescent mental health clinics. Habilitation clinics are typically staffed with pediatricians, child neurologists, psychologists, special educators, social nurses, physiotherapists, and others. Child and adolescent mental health clinics are typically staffed with child psychiatrists, psychologists, special educators, social nurses, and others. How such differences in the professions represented in these clinics may affect diagnostic procedure and age are not known.

The southeastern part of Norway has a population of 2.8 million, and Norway has a total population of 5 million. Southeastern Norway has a higher density of inhabitants than most other regions in Norway, and it includes both rural and city areas. The prevalence of ASD in Norway is estimated at 51 to 60 individuals per 10,000 population (24,25).

This study had two main goals. First, the study investigated the following hypotheses: (1) Preschool children with ASD are diagnosed at the same age in Norway as in other Western countries; and (2) The diagnostic process for preschool children with ASD is standardized and uniform. Second, this study sought to explore factors that may be associated with diagnostic age.

## Methods

### *Participants*

Participants in this study were recruited from the records of special health clinics in the southeastern part of Norway. Sixteen specialist clinics were identified, and 15 consented to patient recruitment. Seven of these clinics were a part of a general child and adolescent mental health trust, and eight were habilitation clinics. The 15 clinics revealed 114 preschool children who had been diagnosed with ASD during the 2011 calendar year: 78 with autistic disorder, 28 with atypical autism, 2 with Asperger syndrome, and 11 with pervasive developmental disorder not otherwise specified. This comprises all of the children who were diagnosed with ASD at these clinics.

Each hospital includes several mental health clinics. For the purpose of analysis, the mental health clinics were grouped together according to hospital.

## Measures

All clinics completed a questionnaire developed by the author for each child diagnosed with ASD during 2011. The questionnaire was developed to assess relevant information regarding diagnostic assessment and the age at diagnosis. The questionnaire first assessed demographic information about each child. It was also used to collect information about how the diagnostic assessment had been conducted, mainly by assessing the standardized diagnostic assessment tools used in each case. The selection of diagnostic assessment tools included in the questionnaire was based on the instruments mentioned in the Regional Practice Parameters for the assessment and diagnosis of ASD. The final diagnostic decision and the child's age at diagnosis are assessed by the questionnaire. The specific questions asked are detailed in Table 2.

**TABLE 2. Elements of the Questionnaire**

Demographic Information	
Specialist clinic	
Sex	
Ethnicity	
Municipality	
Age at referral	
Referring agency	
Diagnostic Process	
<i>Diagnostic Tools</i>	
Social interaction, communication and language, and restricted and repetitive behaviors	
	Autism Diagnostic Observation Schedule (ADOS)
	Autism Diagnostic Interview, Revised (ADI-R)
	Social Communication Questionnaire (SCQ)
	Diagnostic Scale for Social and Communication Disorders (DISCO)
	Childhood Asperger Syndrome Test (CAST)
	Modified Checklist for Autism in Toddlers (M-CHAT)
Cognitive assessment	
	Wechsler Intelligence Scales (WPPSI-R/WPPSI-III)
	Leiter International Performance Scale, Revised (Leiter-R)
	Bayley Scales of Infant and Toddler Development (Bayley)
	Mullen Scales of Early Learning (Mullen)
	Psychoeducational Profile (PEP-3)
	Behavior Rating of Executive Functioning (BRIEF)
Language assessment	
	Språk (6-16)
	Tidlig Registrering Av Språkutvikling (TRAS)
	Reynell Developmental Language Scales (Reynell)
	Children's Communication Checklist II (CCC-2)
	British Picture Vocabulary Test (BPVS)
Adaptive assessment	
	Vineland Adaptive Behavior Scales (VABS)
Other assessments	
	Achenbach System of Empirically Based Assessment (ASEBA)
	Aberrant Behavior Checklist (ABC)
	The Strengths and Difficulties Questionnaire (SDQ)
	Developmental Behavior Checklist (DBC)
Diagnosis	
Diagnostic age	

The professionals involved in the provision of assessment services completed the questionnaires; this included pediatricians, psychologists, and social workers. The data for each participant were retrieved

from each clinic's electronic patient journal by the local professional and then transferred to the questionnaire developed for this study.

Demographic information about the participants is presented in Table 3.

**TABLE 3. Demographic Information**

Participants (n = 115)	
Gender	
Male	95
Female	19
Ethnicity	
European	78
Asian	15
African	16
Mixed	5
Referring Agency	
General practitioner	57
Community health center	19
Children's ward at hospital	17
Child welfare service	8
Specialist pedagogical service	3
Other	10

## Statistical Analysis

The results are presented on the basis of descriptive statistics for the participants. To explore the possible factors that may affect the diagnostic age of the participants in this study, one-way analysis of variance was used for nominal variables; regression was used for all other variables. All analysis was conducted with the use of SPSS software, version 22.

## Results

### Diagnostic Age

The diagnostic age was reported for each individual child and is defined as the child's age in months at diagnosis. The mean diagnostic age of preschool children with ASD was 46.4 months (standard deviation, 13.5 months). The range of diagnostic age was 13 to 75 months, and the median age was 45 months. A minority of 3.5% of the children ( $n = 4$ ) was diagnosed before or at 24 months of age, and 27.2% of the children ( $n = 31$ ) were diagnosed before or at 36 months of age.

### Diagnostic Assessment Procedure

The use of standardized diagnostic assessment tools varied among participants, and the frequencies and percentages of cases for which each diagnostic assessment tool was used are listed in Table 4. The diagnostic assessment tools used did not vary significantly on the basis of whether diagnosis occurred in a mental health clinic or a habilitation clinic.

**TABLE 4.** Frequency of Use of Diagnostic Assessment Tools (n=115)

Diagnostic Assessment Tool	Frequency of Use	Percentage of Cases
ADOS	106	99.2
ADI-R	97	84.3
Others*	68	59.1
VABS	37	32.2
Bayley	31	27.0
WPPSI-R/WPPSI-III	21	18.3
ASEBA	8	7.0
Mullen	7	6.1
SCQ	6	5.2
Reynell	6	5.2
Leiter-R	5	4.3
BPVS	4	3.5
PEP-3	3	2.6
M-CHAT	2	1.7
CAST	1	0.9
BRIEF	1	0.9

\*This category consists of unpublished checklists and diagnostic tools that do not measure social, communication, or behavioral symptoms

**TABLE 5.** Statistics for Each Clinic Included in the Present Study

Clinic No.	Type of Clinic	Number of Children Diagnosed	Age at Referral in Months (Range)	Age at Diagnosis in Months (Range)	Mean No. of Diagnostic Assessment Tools Used	Time From Referral to Diagnosis in Months (Range)	Number of Cases That Followed Published Guidelines
Clinic 1	Habilitation	31	37 (8 to 68)	42 (13 to 71)	4.16	4 (1 to 9)	22
Clinic 2	Habilitation	13	40 (29 to 56)	47 (33 to 68)	3.77	7 (3 to 19)	0
Clinic 3	Mental health	3	38 (27 to 44)	42 (31 to 48)	3.00	4 (3 to 4)	0
Clinic 4	Mental health	1	45	55	3.00	10	0
Clinic 5	Mental health	1	63	71	5.00	8	0
Clinic 6	Mental health	3	57 (49 to 63)	71 (68 to 75)	5.33	14 (9 to 22)	0
Clinic 7	Mental health	14	46 (27 to 63)	52 (33 to 68)	2.79	6 (4 to 10)	0
Clinic 8	Habilitation	7	29 (14 to 45)	38 (24 to 50)	1.00	9 (3 to 32)	0
Clinic 9	Habilitation	4	40 (16 to 68)	47 (29 to 68)	2.75	5 (0 to 13)	0
Clinic 10	Habilitation	3	43 (26 to 54)	46 (26 to 59)	2.67	3 (0 to 5)	0
Clinic 11	Habilitation	3	34 (20 to 46)	39 (26 to 54)	6.20	6 (4 to 8)	1
Clinic 12	Habilitation	5	33 (23 to 42)	40 (27 to 53)	2.40	7 (4 to 11)	0
Clinic 13	Mental health	16	40 (11 to 56)	49 (23 to 65)	3.25	9 (3 to 28)	0
Clinic 14	Mental health	1	30	54	2.00	24	0
Clinic 15	Habilitation	7	38 (25 to 48)	52 (37 to 65)	5.00	14 (1 to 36)	2

The diagnostic assessment procedure included an average of 3.6 standardized assessment tools (range, 1 to 8). The most widely used tools were the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview, Revised. The use of standardized assessment instruments is presented in Table 5. The number of standardized assessment tools used varied significantly ( $p < .001$ ) in accordance with the clinic that was conducting the diagnostic assessment.

Only 25 of 114 (21.7%) diagnostic assessments were conducted in accordance with the Regional Practice Parameters for the assessment and diagnosis of ASD, including the use of the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview, Revised, as well as cognitive and adaptive assessment. Only three clinics reported cases in which the regional guidelines were used in a

significant proportion of the assessments, and all three of these were habilitation clinics. No clinics reported that they were following the guidelines in all cases. Children who were diagnosed on the basis of the regional guidelines had a mean diagnostic age of 38.5 months, whereas children who were diagnosed without following these guidelines had a mean diagnostic age of 48.7 months. This difference in diagnostic age is statistically significant ( $p = .001$ ).

The time required to conduct the diagnostic assessment was defined as the time from referral to a specialist clinic to the reported time of diagnosis. The mean time for all specialist clinics was 7.1 months (standard deviation, 6.1 months; range, 0 to 36 months). The exclusions of assessment times that were more than 12 months only slightly affected the mean time used (5.3 months). The mean diagnostic

assessment time for each clinic varied from 3 months to 24 months, which reveals significant differences among the time used by each clinic. No significant difference was found between children diagnosed at a habilitation clinic and those diagnosed at a mental health clinic ( $p = .197$ ).

### Factors That Affect Diagnostic Age

Analysis reveals that diagnostic age significantly varies in accordance with the type of clinic that conducted the diagnostic assessment ( $p = .048$ ). Children who were diagnosed at child and adolescent mental health clinics had a mean diagnostic age of 56.3 months, and children who were diagnosed in habilitation clinics had a mean diagnostic age of 44.4 months. This difference in diagnostic age was found to be significant ( $p = .023$ ).

The age at referral is naturally correlated with the diagnostic age ( $r = 0.892$ ;  $P < .001$ ). There are no significant relationships between the age at referral and the time spent on the diagnostic assessment. The age at referral did not differ according to the agency that referred the child for assessment, except for the fact that children who are referred through child welfare services are referred significantly later. Analysis did not reveal significant differences in age at referral or at final diagnosis. No other associations related to age at referral were examined.

Diagnostic age did not differ significantly by gender ( $p = .214$ ), and ethnicity did not influence either age at referral ( $p = .132$ ) or age at diagnosis ( $p = .13$ ).

The *International Statistical Classification of Diseases and Related Health Problems, 10th Revision* diagnostic subgroup was associated with age at referral and thus also diagnostic age, although not with regard to the time spent on the diagnostic assessment. Children in subgroups F84.5 (Asperger syndrome) and F84.9 (Pervasive developmental disorder, unspecified) were later referred for diagnostic assessment at a significant rate as compared with children in subgroup F84.1 (Atypical autism) ( $p = .048$  and  $p = .022$ , respectively). Other significant differences were not found among diagnostic subgroups.

### Discussion

The current study examined the diagnostic age of preschool-aged children with ASD. The results show that most of these children in the southeastern region of Norway are diagnosed at a mean age of 46.4 months. This is in line with other international studies (8,17,26-27), and it is considerably later than research has indicated it possible (4, 15). The study also explored the possible factors that affect the diagnostic age of children with ASD.

The diagnostic age varied significantly in accordance with the type of clinic to which the

children were referred. The diagnostic procedure also varied among the different clinics that participated in this study. These results add information to the existing literature to suggest that there are regional and between-clinic differences in the diagnosis of ASD (16,19). The current study also shows that children referred to habilitation clinics are diagnosed earlier than children referred to child and adolescent mental health clinics. Differences in the medical staff members who typically provide services may be a factor that contributes to this difference. In addition, children with the most severe and typical symptoms of ASD are traditionally referred to habilitation clinics, and children with more subtle features associated with ASD are traditionally referred to child and adolescent mental health clinics. The current study—like other studies before it (17,27)—found that certain subgroups within the autism spectrum were associated with certain diagnostic ages. For example, children in subgroups F84.5 (Asperger syndrome) and F84.9 (Pervasive developmental disorder, unspecified) were diagnosed later than children in subgroups F84.0 (Childhood autism) and F84.1 (Atypical autism). Children with the first two diagnoses are described with more subtle symptoms at a young age than children with the later diagnoses. The children diagnosed with Asperger syndrome and Pervasive developmental disorder, unspecified, were all diagnosed at child and adolescent mental health clinics. This strengthens the notion that children referred to mental health clinics often have more subtle symptoms.

The variations in diagnostic procedures and processes may pose a challenge to the national goals of equality in health services, especially because only 21.7% of diagnostic assessment were found to have been conducted in accordance with the regional practice parameters. This low number is still higher than that found when examining the use of standardized diagnostic instruments in other samples (19). Further investigations should examine barriers to the implementation of practice parameters and address how organizations may facilitate the use of practice parameters and standardized assessment instruments.

Previous research has proposed that gender and ethnicity may influence the diagnostic age of children with ASD (21,27). However, this study confirmed the findings of more recent research that there is no significant association between sex, ethnicity, and age at diagnosis (21). The primary health services being delivered at community centers and by physicians who are free of charge may contribute to more equality across ethnicities than has been found in studies conducted in other countries.

One important factor that affects the diagnostic age of children with ASD is the age at referral to a

specialist clinic for formal diagnostic assessment. This study found that the age at referral did not differ significantly among the referring agencies, except for children who were referred through child welfare services. Several factors may contribute to the late referral, including comorbid conditions and challenges as a result of parental reluctance (15,18,20,28). All referring agencies in Norway observe children during consultations that last from 20 to 60 minutes, and there are often several months between such consultations. This system may contribute to the later diagnostic age of children with ASD in Norway. The identification of the atypical development that is associated with ASD requires the systematic observation of behavioral patterns that are somewhat consistent across time and settings. This study shows that most children with ASD are diagnosed at an older age than research indicates to be possible, and the system for referral in Norway may contribute to this later diagnosis. Shifting the detection of ASD into arenas that involve the continuous observation of a child's development (e.g., day care centers) may facilitate the identification and diagnosis of ASD at a younger age.

The time span from referral to a specialist clinic to actual diagnosis was found in this study to stretch out over several months. This time span may not be explained by extended use of standardized diagnostic instruments, and no significant association between the number of standardized diagnostic instruments and the length of the diagnostic assessment period was found. For some children, the early identification of ASD may be required for effective early intervention. Hence, the exploration of the factors that contribute to the lengthy assessment period may be important to improve the provision of services to young children with ASD. Most diagnostic assessments of young children with possible ASD are conducted in outpatient clinics. This may lead to diagnostic assessments that consist of one appointment for each activity that makes up the diagnostic assessment. The organization of diagnostic assessments into single activities at different points in time may be driven by the system of economic reimbursement for Norwegian hospitals. The conduction of the diagnostic assessment via single assessment appointments may contribute to the lengthy time span of diagnostic assessments in Norway. Organizing the diagnostic assessment procedure in a manner that allows several observations, assessments, and examinations to occur during each appointment at the outpatient clinic may help to shorten the time span of the diagnostic assessment.

According to Norwegian regulations, children are entitled to receive certain health services within a predefined time frame. For children between the age

of 0 and 2 years, health services should be provided within 4 weeks. The corresponding time frame for children between the ages of 3 and 6 years is 6 weeks. This time frame is most likely included in the time used on diagnostic assessment procedure, but according to Norwegian authorities it should be a maximum waiting time.

This study has not collected information about the quality of the diagnostic classification of specific cases or clinics. No information was collected regarding the reliability of standardized assessment tools or final diagnostic conclusions. The only parameter that was used to indicate quality in this study was whether or not the regional guidelines were used. The results indicate that children who are referred to clinics in accordance with the regional guidelines are diagnosed at a younger age and thus may indicate the quality of their assessments and close cooperation with referring agencies.

This study included all children diagnosed with ASD at the included clinics over the course of 1 year, and information from the official records of each child was collected. Several factors still indicate that the results should be interpreted with caution. One year is a relatively short period for data collection, and the diagnostic age may lead to cohort effects not being adjusted for appropriately. Only children who are younger than school age (i.e., those <6 to 7 years old) were included in the study, so children who were diagnosed later may be missed. This indicates that the actual mean diagnostic age may be even higher than that found in this study. This study also did not collect information about comorbidities, which may influence the diagnostic assessment procedure, the time spent on diagnostic assessment, and the diagnostic age.

Children with ASD make up a heterogeneous group that differs widely with regard to the diversity and severity of symptoms. For some children with ASD, the symptoms of the impairment do not become relevant or apparent when they are young, and a formal diagnosis will not be relevant during the early years. It may not be possible or necessary to diagnose all children with ASD when they are 3 years old or younger.

### **Clinical Significance**

Norwegian children with ASD are identified and diagnosed considerably later than the age research has indicated to be optimal for reliable and valid diagnosis. Differences in diagnostic procedures and clinic types seem to be associated with diagnostic age. The procedures for referral and the agencies responsible for referral to diagnostic assessment may also contribute to a later diagnostic age.

## References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. Washington, D.C.: American Psychiatric Association; 2013.
2. World Health Organization. International classification of diseases and related health problems - 10th revision - 2<sup>nd</sup> edition. Geneva: World Health Organization; 2004.
3. Jones EJ, Gliga T, Bedford R, Charman T, Johnson MH. Developmental pathways to autism: a review of prospective studies of infants at risk. *Neurosci Biobehav Rev* 2014;39C:1-33.
4. Zwaigenbaum L, Bryson S, Garon N. Early identification of autism spectrum disorders. *Behav Brain Res* 2013;251:133-46.
5. Rogers SJ, Vismara L, Wagner AL, McCormick C, Young G, Ozonoff S. Autism treatment in the first year of life: a pilot study of infant start, a parent-implemented intervention for symptomatic infants. *J Autism Dev Disord* 2014; DOI 10.1007/s10803-014-2202-y
6. Wetherby AM, Guthrie W, Woods J, Schatschneider C, et al. Parent-implemented social intervention for toddlers with autism: An RCT. *Pediatrics* 2014;134(6): DOI 10.1542/peds.2014-0757
7. Koegel LK, Singh AK, Koegel RL, Hollingsworth JR, Bradshaw J. Assessing and Improving Early Social Engagement in Infants. *J Posit Behav Interv* 2013. DOI: 10.1177/1098300713482977
8. Stenberg N, Bresnahan M, Gunnes N, et al. Identifying children with autism spectrum disorder at 18 months in a general population sample. *Paediatr Perinat Epidemiol* 2014;28(3):255-62.
9. Samango-Sprouse CA, Stapleton EJ, Aliabadi F, et al. Identification of infants at risk for autism spectrum disorder and developmental language delay prior to 12 months. *Autism* 2014;19(3):327-37.
10. Koterba EA, Leezenbaum NB, Iverson JM. Object exploration at 6 and 9 months in infants with and without risk for autism. *Autism* 2014;18(2):97-105.
11. Ozonoff S, Young GS, Landa RJ, et al. Diagnostic stability in young children at risk for autism spectrum disorder: a baby siblings research consortium study. *J Child Psychol Psychiatry* 2015;56(9):988-98.
12. Mazurek MO, Handen BL, Wodka EL, Nowinski L, Butter E, Engelhardt CR. Age at first autism spectrum disorder diagnosis: the role of birth cohort, demographic factors, and clinical features. *J Dev Behav Pediatr* 2014;35(9):561-9.
13. Barbaro J, Dissanayake C. Autism spectrum disorders in infancy and toddlerhood: a review of the evidence on early signs, early identification tools, and early diagnosis. *J Dev Behav Pediatr* 2009;30(5):447-59.
14. Shattuck PT, Durkin M, Maenner M, et al. Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *J Am Acad Child Adolesc Psychiatry* 2009;48(5):474-83.
15. Daniels AM, Halladay AK, Shih A, Elder LM, Dawson G. Approaches to enhancing the early detection of autism spectrum disorders: a systematic review of the literature. *J Am Acad Child Adolesc Psychiatry* 2014;53(2):141-52.
16. Lord C, Petkova E, Hus V, et al. A multisite study of the clinical diagnosis of different autism spectrum disorders. *Arch Gen Psychiatry* 2012;69(3):306-13.
17. Bickel J, Bridgemohan C, Sideridis G, Huntington N. Child and family characteristics associated with age of diagnosis of an autism spectrum disorder in a tertiary care setting. *J Dev Behav Pediatr* 2015;36(1):1-7.
18. Daniels AM, Mandell DS. Explaining differences in age at autism spectrum disorder diagnosis: a critical review. *Autism* 2014;18(5):583-97.
19. Wiggins LD, Reynolds A, Rice CE, et al. Using standardized diagnostic instruments to classify children with autism in the study to explore early development. *J Autism Dev Disord* 2015;45(5):1271-80.
20. Mishaal RA, Ben-Itzhak E, Zachor DA. Age of autism spectrum disorder diagnosis is associated with child's variables and parental experience. *Res Autism Spectr Disord* 2014;8(7):873-80.
21. Giarelli E, Wiggins LD, Rice CE, et al. Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disabil Health J* 2010;3(2):107-16.
22. Volkmar F, Siegel M, Woodbury-Smith M, et al. Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *J Am Acad Child Adolesc Psychiatry* 2014;53(2):237-57.
23. Regional kompetansetjeneste for autisme, ADHD, Tourettes syndrom og narkolepsi. Regional guidelin for the diagnosis of autism spectrum disorders [Regional retningslinje for diagnostisering av autismspekterforstyrrelser]. Oslo: Oslo universitetssykehus HF, 2013.
24. Isaksen J, Diseth TH, Schjølberg S, Skjeldal OH. Observed prevalence of autism spectrum disorders in two Norwegian counties. *Eur J Paediatr Neurol* 2012;16(6):592-8.
25. Surén P, Bakken IJ, Lie KK, et al. Differences across counties in the registered prevalence of autism, ADHD, epilepsy and cerebral palsy in Norway. *Tidsskr Nor Laegeforen* 2013;133(18):1929-34
26. Chawarska K, Paul R, Klin A, Hannigen S, Dichtel LE, Volkmar F. Parental recognition of developmental problems in toddlers with autism spectrum disorders. *J Autism Dev Disord* 2007;37(1):62-72.
27. Shattuck PT, Durkin M, Maenner M, et al. Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *J Am Acad Child Adolesc Psychiatry* 2009;48(5):474-83.
28. Crais ER, Watson LR. Challenges and opportunities in early identification and intervention for children at-risk for autism spectrum disorders. *Int J Speech Lang Pathol* 2014;16(1):23-9.
29. Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children. *JAMA* 2001;285(24):3093-9.
30. Magnusson P, Sæmundsen E. Prevalence of autism in Iceland. *J Autism Devel Disord* 2001;31(2):153-63.
31. Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among medicaid-eligible children with autism. *J Am Acad Child Adolesc Psychiatry* 2002;41(12):1447-53
32. Lingam R. Prevalence of autism and parentally reported triggers in a north east London population. *Arch Dis Child* 2003;88(8):666-70.
33. Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. *JAMA* 2003;289(1).
34. Daley TC. From symptom recognition to diagnosis: children with autism in urban India. *Soc Sci Med* 2004;58(7):1323-35.
35. Keen D, Ward S. Autistic spectrum disorder: a child population profile. *Autism* 2004;8(1):39-48.
36. Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children: confirmation of high prevalence. *Am J Psychiatry* 2005;162(6):1133-41.
37. Juneja M, Mukherjee SB, Sharma S. A descriptive hospital based study of children with autism. *Indian Pediatr* 2004;42:453-8

38. Mandell DS, Novak MM, Zubritsky CD. Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics* 2005;116(6):1480-6.
39. Goin-Kochel RP, Mackintosh VH, Myers BJ. How many doctors does it take to make an autism spectrum diagnosis? *Autism* 2006;10(5):439-51.
40. Wiggins LD, Baio JON, Rice C. Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *J Dev Behav Pediatr* 2006;27(Suppl 2):S79-S87.
41. Latif AH, Williams WR. Diagnostic trends in autistic spectrum disorders in the South Wales valleys. *Autism* 2007;11(6):479-87.
42. Oslejskova H, Kontrova I, Foralova R, Dusek L, Nemethova D. The course of diagnosis in autistic patients: the delay between recognition of the first symptoms by parents and correct diagnosis. *Neuro Endocrinol Lett* 2007;28(6):895-900.
43. Chen CY, Liu CY, Su WC, Huang SL, Lin KM. Urbanicity-related variation in help-seeking and services utilization among preschool-age children with autism in Taiwan. *J Autism Dev Disord* 2008;38(3):489-97.
44. Parner ET, Schendel DE, Thorsen P. Autism prevalence trends over time in Denmark: changes in prevalence and age at diagnosis. *Arch Pediatr Adolesc Med* 2008;162(12):1150-6.
45. Williams E, Thomas K, Sidebotham H, Emond A. Prevalence and characteristics of autistic spectrum disorders in the ALSPAC cohort. *Dev Med Child Neurol* 2008;50(9):672-7.
46. Hertz-Picciotto I, Delwiche L. The rise in autism and the role of age at diagnosis. *Epidemiology* 2009;20(1):84-90.
47. Nassar N, Dixon G, Bourke J, et al. Autism spectrum disorders in young children: effect of changes in diagnostic practices. *Int J Epidemiol* 2009;38(5):1245-54.
48. Ouellette-Kuntz H, Coe H, Lam M, et al. Age at diagnosis of autism spectrum disorders in four regions of Canada. *Can J Public Health* 2009;100(3):268-73.
49. Perryman TY. Investigating disparities in the age of diagnosis of autism spectrum disorders. The University of North Carolina at Chapel Hill; 2009.
50. Adelman CR. Factors that influence age of identification of children with autism and pervasive developmental disorder NOS. University of Houston; 2010.
51. Mandell DS, Morales KH, Xie M, Lawer LJ, Stahmer AC, Marcus SC. Age of Diagnosis Among Medicaid-Enrolled Children With Autism, 2001–2004. *Psychiatr Serv* 2010;61(8):822-9.
52. Noterdaeme M, Hutzelmeyer-Nickels A. Early symptoms and recognition of pervasive developmental disorders in Germany. *Autism* 2010;14(6):575-88.
53. Chamak B, Bonniau B, Oudaya L, Ehrenberg A. The autism diagnostic experiences of French parents. *Autism* 2011;15(1):83-97.
54. Fountain C, King MD, Bearman PS. Age of diagnosis for autism: individual and community factors across 10 birth cohorts. *J Epidemiol Community Health* 2011;65(6):503-10.
55. Frenette P, Dodds L, MacPherson K, Flowerdew G, Hennen B, Bryson S. Factors affecting the age at diagnosis of autism spectrum disorders in Nova Scotia, Canada. *Autism* 2013;17(2):184-95.
56. Kalkbrenner AE, Daniels JL, Emch M, Morrissey J, Poole C, Chen JC. Geographic access to health services and diagnosis with an autism spectrum disorder. *Ann Epidemiol* 2011;21(4):304-10.
57. Rosenberg RE, Landa R, Law JK, Stuart EA, Law PA. Factors affecting age at initial autism spectrum disorder diagnosis in a national survey. *Autism Res Treat* 2011: DOI 10.1155/2011/874619
58. Coe H, Ouellette-Kuntz HMJ, Lam M, et al. Correlates of age at diagnosis of autism spectrum disorders in six Canadian regions. *Chronic Dis Inj Canada* 2012;32(2):90-100.
59. Valicenti-McDermott M, Hottinger K, Seijo R, Shulman L. Age at diagnosis of autism spectrum disorders. *J Pediatr* 2012;161(3):554–6.
60. Mazurek MO, Handen BL, Wodka EL, Nowinski L, Butter E, Engelhardt CR. Age at first autism spectrum disorder diagnosis. *J Dev Behav Pediatr* 2014;35(9):561–9.
61. Jo H, Schieve LA, Rice CE, et al. Age at autism spectrum disorder (ASD) diagnosis by race, ethnicity, and primary household language among children with special health care needs, United States, 2009–2010. *Matern Child Health J* 2015;19(8):1687-97.