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REVIEW

Prevalence of Autism in Scandinavian Countries (Denmark, Norway, Sweden), and Nordic Countries (Finland, Iceland, the Faroe Islands, and Greenland)

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Aim: This study aims to identify and describe prevalence rates for ASD in the Scandinavian countries (Denmark, Norway, Sweden), as well as the Nordic countries (Finland, Iceland, the Faroe Islands, and Greenland).

Methods: A systematic review was conducted following PRISMA (2009) guidelines and based on the two databases: APA PsycINFO and MEDLINE (PubMed).

Results: A total of 13 studies were included in the analyses. It was not possible to identify ASD prevalence studies for Greenland. However, for the remaining countries descriptive increases in ASD prevalence figures were observed. Increases were evident both in relation to age and birth cohort. Studies varied regarding which age group and cohort prevalence figures were reported. The most reported age group was the 7–12-year-olds. In this group, recent prevalence figures for Denmark ranged from 0.26% to 1.47%, in Norway 0.6%, in Sweden 0.23–0.68%, in Finland 0.22–0.86%, and in Iceland 2.40–3.13%. Iceland stood out in terms of higher prevalence figures compared to the other Scandinavian and Nordic countries. Two studies from the Faroe Islands reported ASD prevalence rates between 0.50% and 0.94% for 7–24-year-olds. These studies were based on nationwide figures, but not from national or official registers.

Discussion and conclusion: This study documented increasing prevalence of ASD in Scandinavian and Nordic countries. Several explanations of aspects that may contribute to the increases were discussed, eg, heightened awareness of ASD and earlier diagnosis. The importance of considering differences in data sources was discussed, with an emphasis on the importance of using national registries when available as this source is the most reliable and valid. The absence of prevalence figures for Greenland may be attributed to structural as well as cultural aspects, eg, two parallel systems assessing ASD, cultural taboos as well as lack of awareness of ASD. Suggestions or how to gain knowledge on ASD prevalence in Greenland is presented.

Keywords: autism spectrum disorder, prevalence, Scandinavia, Nordic

Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition.[1] In accordance with the diagnostic criteria, individuals with ASD experience three behavioural disturbances consisting of social abilities, language impairment, and stereotyped, repetitive patterns of behaviour.[2] The description of ASD in The International Classification of Diseases and Related Health Problems 11th edition is as follows:

> Autism spectrum disorder is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context.[3]

Although ASD is influenced by genetic factors, the precise biological implications are still being debated.[4] Genetic explanations are supported by twin and family studies.[2,5,6] ASD is predominantly defined through behavioural assessment and is therefore often referred to as a behavioural diagnosis. The limitations of assessing psychiatric disorders through behaviour are that members of the respective diagnostic group often show high levels of heterogeneity as

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different individuals are affected to different degrees.[4] Hence, making a generalization about the experiences of individuals living with ASD is challenging[7] and recent attempts have been to evaluate ASD as a spectrum disorder. The large heterogeneity is also a challenge in research investigating the disorder[8] and hinders precise prognostic explanations for parents, given the wide spectrum of potential lifelong challenges of ASD. ASD is more prevalent in males than females.[9] While some individuals with ASD can live without significant support in adult life, others may never acquire a functional language or be able to develop interpersonal relationships.

Diagnostic Categories of ASD

The understanding of ASD has evolved over the years. It is now 80 years since Leo Kanner first described *infantile autism* in 1943, and it took nearly 40 years for the diagnosis to receive an official recognition. Since then, the ASD diagnosis has undergone several changes, with both the description of the diagnosis and the terminology changing over time.[10] This is reflected in the two main official manuals for diagnosing mental disorders: The International Classification of Diseases and Related Health Problem (ICD) and the Diagnostic and Statistical Manual of Mental Disorder (DSM). ICD functions as a coding system adopted by member countries of the World Health Organisation (WHO), while DSM serves as the diagnostic tool published by American Psychiatric Association (APA). ICD and DSM are widely accepted worldwide, and they have created a common language within psychiatry and psychology.[11] Given that this study is focused on ASD prevalence in the Nordic and Scandinavian countries, where the ICD is the manual used for diagnostic purposes, we will not focus on categories present in the DSM.

The most recent revised manual of the ICD is the ICD-11 and the ICD-10's criteria requiring symptom onset prior to 3 years of age has been replaced with a less restrictive onset during the early developmental period, thereby underlying a caution that some symptoms may not fully manifest until later in life when social demands exceed capacities[10] (p. 4259). Symptoms can therefore occur at an early age but may also not become apparent before adulthood for some individuals. The ICD-11, however, has not yet been integrated in practice. The ICD-10 has seven categories consisting of Pervasive Developmental Disorder, *Childhood Autism*, Rett Syndrome, Another Childhood disintegrative disorder, Asperger's disorder, Pervasive Developmental Disorder not Specified and *Atypical Autism.*[12]

Some differences arise as to when Nordic and Scandinavian countries have adopted newer versions of either ICD. For instance, Denmark used ICD-8 from 1987 to 1993, and thereafter switched to ICD-10 from 1994.[13] Hence, ICD-9 was never implemented in Denmark.[14] In Sweden ICD-9 was used from 1987 to 1996, and thereafter ICD-10 from 1997 to present. In Finland ICD-9 was used from 1987 to 1995, and thereafter ICD-10 from 1996 to present.[13] Over the years, the Nordic countries consisting of Denmark, Norway, Sweden, Finland, Iceland, The Faroe Islands and Greenland have not necessarily modified their diagnostic systems at the same time. This has influenced the conceptualization and understanding of ASD in each country and ultimately likely influenced the ASD prevalence figures to some degree.

Consequences of Living with ASD

Individuals living with ASD frequently encounter *stigma* and *stereotypes* associated with their diagnosis. This applies to both *public stigma* and *internalised stigma*, both of which have been linked to poor mental health.[15] Moreover, it is also believed that individuals with ASD have a greater risk of developing psychiatric problems.[16] ASD is therefore more than just a clinical diagnosis because it influences an individual's identity and quality of life significantly.[17] Greater knowledge about the prevalence of ASD in a specific country is valuable for influencing stakeholders and politicians in their decision-making related to promoting national health and possibilities for education to all.

Prevalence

It is important to explain the distinction between *prevalence* and *incidence* as these terms are often misinterpreted as having the same meaning.[18] Prevalence is: "…number of existing disease cases in a defined group of people during a specific time period", whereas incidence is: "…number of new cases of disease in a defined group of people over a specific time"[19] (p. 69) Prevalence is therefore presenting the existing cases over a specific period, whereas incidence expresses the number of newly emerging cases.[20] The current study focuses on prevalence.

In recent decades, there has been a rapid increase in the prevalence of ASD, particularly in regions such as Asia, Europe, and North America[21] with a consistent rise in the number of individuals diagnosed with ASD.[22] The rising prevalence figures are a global phenomenon, and there has also been an increase in the number of studies conducted in under-represented countries. This is a positive development, as it contributes to a more advanced scientific discovery of autism aetiology and can help under-represented countries and regions to address more specific needs.[23] The analysis of prevalence data gives an opportunity to provide valuable insights to policymakers and public health services to develop strategic and beneficial plans.[21] The examination of prevalence data also provides an opportunity to understand and explain trends within ASD. Prevalence data therefore play an important role in forming policies regarding facilitation of essential services for individuals with ASD and their families. Examining prevalence data can be conducted at a global, national, and local level.

Gender Ratio and Prevalence

The ASD diagnosis is characterized by the consistent predominance of boys in various ASD prevalence studies.[7,23] A systematic review conducted by Loomes et al[9] found a gender ratio of three to one among children meeting criteria for ASD. This suggests that there is a likelihood of high-functioning females with ASD going undetected. In a qualitative study by Milner et al,[24] women diagnosed with ASD reported adopting strategies, also called *masking*, and *camouflaging* to better fit in with societal expectations. For instance, some girls consciously rote learned specific phrases to be able to contribute to conversations, while others studied the amount of time an individual maintains eye contact to enhance their social interaction skills (ibid). Women also reported that camouflaging can be helpful in some instances, such as in education, employment and when making friends, but can also have negative consequences by limiting the individual in receiving appropriate support. Camouflaging may also contribute to individuals receiving their diagnosis later in life than they ideally should.[25] Males with ASD can also make use of camouflaging. However, the term is often used to explain the missing or late diagnosis of females with ASD.[26] Furthermore, camouflaging is associated with stress, depression, exhaustion, and identity confusion.[27]

Overall, males are more predisposed to receiving an ASD diagnosis than females.[28] This raises concerns regarding the possible under-identification of females with ASD, leading to unmet mental health needs, but also difficulties in females gaining a diagnosis.[24,29]

The current review has a focus on prevalence of ASD at the national level, specifically focusing on the seven Nordic countries consisting of Denmark, Norway, Sweden, Finland, Iceland, the Faroe Islands and Greenland.

The aim of the current study is twofold: first, we present results from a systematic literature review of prevalence reported for the seven Nordic countries, and second, we discuss what may be affecting the reported ASD prevalence figures, and how differences between the Nordic countries might be contributing to variations in ASD prevalence figures. The central research questions guiding this study are: What is the ASD prevalence in the Nordic countries: Denmark, Norway, Sweden, Finland, Iceland, the Faroe Islands, and Greenland, and what factors contribute to the development and descriptive variations in these prevalence figures?

Methods

To uncover ASD prevalence figures, a systematic literature review was conducted. Our systematic review adhered to PRISMA 2009 guidelines[30] to ensure clarity and transparency. This study examines ASD prevalence studies across the seven Nordic countries emphasizing the need to acknowledge potential variations in diagnostic categories and study designs. According to Fombonne,[18] there is no standardized method or study design for examining prevalence, and this can have an impact on prevalence rates and their accuracy.[31]

Search Procedure

Searches were conducted to identify studies concerning ASD and prevalence with an additional search for each individual country included in this study. The final systematic search was carried out on 18 October 2023. Two electronic databases were used consisting of APA PsycINFO and MEDLINE (PubMed). The search was limited to peer-reviewed articles, and the search strings used are shown in Supplementary Table 1. RefWorks was used for importing, storing, and managing reference information.

Inclusion and Exclusion Criteria

Studies were included if they: 1) reported prevalence data for either Denmark, Norway, Sweden, Finland, Iceland, the Faroe Islands or Greenland, 2) were based on an official or national register, or 3) were nationwide studies. Studies were excluded if they did not meet the above inclusion criteria, or if they: 1) reported incidence and no prevalence, 2) did not report on prevalence across subgroups ASD 3) reported ASD prevalence exclusively in individuals who also have an intellectual disability, 4) were citywide studies, or 6) not published in English. These exclusion criteria were necessary to compare prevalence across countries and studies.

Results

After duplicates were removed, 476 studies were screened for title and abstract. Thereafter, 46 studies were full-text screened, and 11 studies were included in the final synthesis (see Figure 1). We first present results from the studies based on national or official registers followed by the results from nationwide, but not official registers.

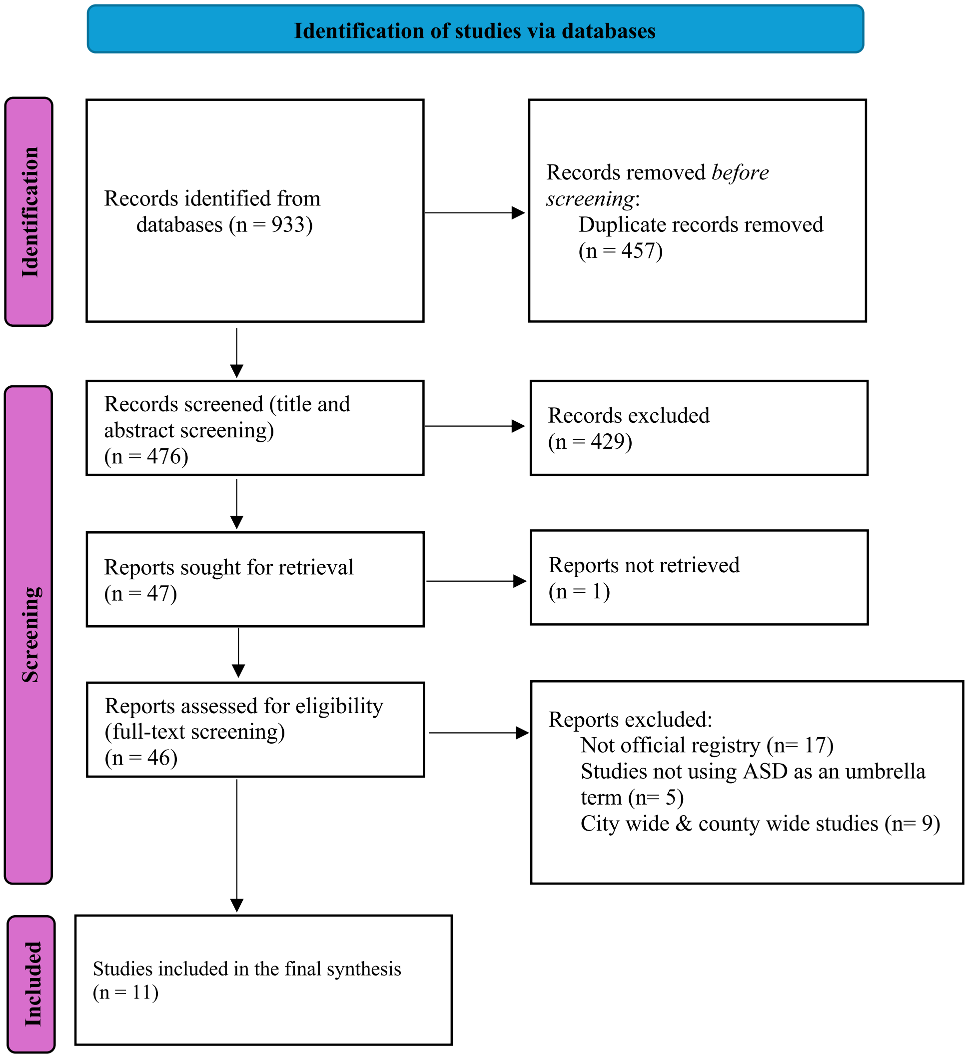

Figure 1 Prisma Flow Diagram.

Notes: Two not official registry studies were included ad hoc in analyses for Faroe Islands. PRISMA figure adapted from Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. PLoS Med. 2009;6(7):1–28.[30]

ASD Prevalence Figures in Denmark, Norway, Sweden, Finland, and Iceland

ASD Prevalence figures from a total of 11 national or official registry studies were included. No studies of national or official registry data were available for Faroe Islands. We therefore included two prevalence studies for Faroe Islands in the analyses, which were based on pragmatic procedures for data collection. Prevalence figures were only available for six of the seven countries: Denmark, Norway, Sweden, Finland, Faroe Islands and Iceland. For Greenland, no prevalence studies were identified. The overview presented in Table 1 encompasses details from the studies such as data source, geographic level, year of birth (cohort), age, the diagnostic system, and gender ratio that influence the respective prevalence figures. Despite these complexities, some clear trends stand out.

One of the initial findings is that Denmark is the country with the highest number of prevalence studies, reaching five nationwide ASD prevalence studies. Four prevalence studies were identified for Norway, and two prevalence studies were identified for Sweden, Finland, and Iceland, respectively. It is important to emphasize that the reported number of prevalence studies is a result of the specific search procedure for the current systematic review which adhered to certain inclusion and exclusion criteria. Specifically, in the case of Sweden, there were initially several citywide prevalence studies identified (eg, for Gothenburg and Stockholm). However, these were excluded as one of our inclusion criteria was the requirement of nationwide studies.

Another noteworthy result is the observed overall expected trend of a descriptive rising prevalence of ASD. The prevalence figures of ASD increased with age, within a given birth cohort and over time, illustrating a rising number of ASD diagnoses throughout the years.

Turning to Norway, the most recent nationwide ASD prevalence study conducted by Özerk and Cardinal[38] suggests a prevalence of 0.18% for 1–5-year-olds born in 2011 to 2015 and 0.41% for 6–16-year-olds born in 2000 to 2010. Notably, this study differs from the three nationwide ASD prevalence studies in Norway, which report figures closer to 0.6–0.76%[36,37,41] and thus seem more comparable with results from the other Scandinavian countries. The results from studies conducted in Denmark, Norway, Sweden, and Finland are generally comparable. The figures from Iceland, however, stand out as an exception, displaying a noticeable higher level of ASD prevalence. According to the Icelandic study conducted by Delobel-Ayoub et al,[35] the prevalence of ASD in Iceland reached up to 3.13% for 8-year-olds born in 2007, which contrasts with figures observed in the same age group and same cohort in other Nordic countries (for Finland, the prevalence was 0.77 and for Denmark, it was 1.26).

This result also differs from other nationwide ASD prevalence studies conducted in Iceland. A study conducted by Saemundsen et al[40] found a much lower ASD prevalence figure of 1.2% among 11–15-year-olds born in the years 1994–1998 in Iceland. When examining the specifics of the two studies conducted in Iceland, it is noteworthy that Delobel-Ayoub et al[35] focused on 7–9-year-olds, while Saemundsen et al[40] examined 11–15-year-olds. However, this age difference alone does not explain the large variance in prevalence. A potential structural explanation for this difference is suggested by the authors, namely that until 2010 only two institutions in Iceland formally diagnosed ASD: The Department of Child and Adolescent Psychiatry, University Hospital (DCAP) and The State Diagnostic and Counselling Centre (SDCC).[35] So when the study by Saemundsen et al[40] was conducted only two databases were available, while three new sources of data were introduced resulting in five entire data sources available when the Delobel-Ayoub et al[35] study was conducted. Furthermore, according to Delobel-Ayoub et al,[35] Iceland has made significant changes in diagnostic services for children with ASD since 2010. The notably higher prevalence of Iceland in Delobel-Ayoub et al,[35] compared with the other Nordic countries, remains a matter that requires further investigation.

To illuminate the gender ratio in prevalence, we included the reported percentage of boys having an ASD diagnosis in studies where the information was available. The findings regarding gender ratio indicate that studies reporting the percentage of boys diagnosed with ASD all exceed 73%. This observation aligns closely with the estimated gender ratio for ASD of three to one, as described in the literature by Loomes et al.[9]

ASD Prevalence Figures in the Faroe Islands and Greenland

The absence of studies reporting the prevalence of ASD from national or official registries for the Faroe Islands and the total absence of knowledge regarding ASD prevalence for Greenland are noteworthy results that must be considered. To

Table 1 Nationwide Studies on ASD Prevalence Shown in per Hundred (%) for Denmark, Norway, Sweden, Finland & Iceland

Country	Data Year/s	Study	Data source	Geographic level	Birth Year (cohort)	Age	Diagnostic system	Prevalence %	Gender
Denmark	2004	Parner, Thorsen, Dixon, de Klerk, Leonard, Nassar, Bourke, Bower & Glasson (2011)[32]	National Registry	Nationwide	1994–1995	9–10	ICD-10	0.66%	84% male
					1996–1997	7-8	ICD-10	0.56%	83% male
					1998–1999	5–6	ICD-10	0.40%	82% male
	2006	Parner, Schendel & Thorsen (2008)[33]	National registry	Nationwide	1994-1995	13	ICD-10	0.82%	N/A
					1996-1997	11	ICD-10	0.74%	
					1998-1999	9	ICD-10	0.62%	
	1990–2007	Atladottir, Gyllenberg, Langridge, Sandin, Hansen, Leonard, Gissler, Reichenberg, Schendel, Bourke, Hultman, Grice, Buxbaum & Parner (2015)[13]	Official registry	Nationwide	1990–1992	5	ICD-8	0.09%	N/A
					1993–1995	5	ICD-8/ICD-10	0.17%	
					1996–1998	5	ICD-10	0.24%	
					1999–2001	5	ICD-10	0.30%	
					2002–2004	5	ICD-10	0.34%	
					2005-2007	5	ICD-10	0.36%	
					1990–1992	8	ICD-8	0.26%	
					1993–1995	8	ICD-8/ICD-10	0.43%	
					1996–1998	8	ICD-10	0.55%	
					1999–2001	8	ICD-10	0.74%	
					2002–2004	8	ICD-10	0.89%	
					1990–1992	10	ICD-8	0.40%	
					1993–1995	10	ICD-8/ICD-10	0.59%	
					1996–1998	10	ICD-10	0.77%	
					1999–2001	10	ICD-10	1.1%	
					1990–1992	15	ICD-8	0.73%	
					1993–1995	15	ICD-8/ICD-10	1.2%	
					1996–1998	15	ICD-10	1.6%	
					1990–1992	22	ICD-8	1.09%	
	2011	Hansen, Schendel & Parner (2015)[34]	National registry	Nationwide	1980–1981	0–13	ICD-10	0.03%	N/A
					1980-1981	14-15	ICD-10	0.01%	
					1980-1981	16–31	ICD-10	0.16%	
					1982–1983	0-11		0.04%	
					1982–1983	12–13		0.02%	
					1982-1983	14-29		0.3%	
					1984–1985	0–9		0.04%	
					1984-1985	10-11		0.01%	
					1984-1985	12–27		0.43%	
					1986–1987	0-7		0.03%	
					1986–1987	8–9		0.01%	
					1986-1987	10-25		0.54%	
					1988–1989	0–5		0.02%	
					1988-1989	6-7		0.03%	
					1988-1989	8–23		0.72%	
					1990–1991	0-3		0.01%	
					1990–1991	4–5		0.01%	
					1990-1991	6-21		0.98%	
	2015	Delobel-Ayoub, Saemundsen, Gissler, Ego, Moilanen, Ebeling, Rafnsson, Klapouszczak, Thorsteinsson, Arnaldsdóttir, Roge, Arnaud & Schendel (2020)[35]	National Registry	Nationwide	2006	9		1.47%	81% male
					2007	8		1.26%	80% male
					2008	7		0.98%	79% male
Norway	2008–2011	Surén, Bakken, Lie, Schjølberg, Aase, Reichborn-Kjennerud, Magnus, Øyen, Svendsen, Aaberg, Andersen & Stoltenberg (2013)[36]	National Registry	Nationwide	1999–2011	6–12	ICD-10	0.6%	N/A
	2016	Surén, Havdahl, Øyen, Schjølberg, Reichborn-Kjennerud, Magnus, Bakken & Stoltenberg (2019)[35]	National Registry	Nationwide	2006–2014	2–8	ICD-10	0.7%	84% male
	2014	Kiselev, Handal, Hjellvik, Reichborn-Kjennerud, Stoltenberg, Surén, Havdahl & Skurtveit (2020)[37]	National Registry	Nationwide	1997–2012	2–7	ICD-10	0.76%	75% male
	2016	Özerk & Cardinal (2020)[38]	National Registry	Nationwide	2011–2015	1–5	ICD-10	0.18%	83% male
					2000-2010	6-16		0.41%	78% male

Sweden	1993–2002	Lundström, Reichenberg, Anckarsäter, Lichenstein & Gilberg (2015)[39]	National registry	Nationwide	1993	9–12	ICD-9	0.23%	N/A
					1994	5	ICD-10	0.30%	
					1995	5	ICD-10	0.32%	
					1996	5	ICD-10	0.39%	
					1997	5	ICD-10	0.45%	
					1998	5	ICD-10	0.47%	
					1999	8	ICD-10	0.60%	
					2000	8	ICD-10	0.60%	
					2001	8	ICD-10	0.53%	
					2002	8	ICD-10	0.50%	
	1990–2007	Atladottir, Gyllenberg, Langridge, Sandin, Hansen, Leonard, Gissler, Reichenberg, Schendel, Bourke, Hultman, Grice, Buxbaum & Parner (2015)[13]	Official registry	Nationwide	1990–1992	10	ICD-9	0.049%	N/A
					1993–1995	10	ICD-9	0.043%	
					1996–1998	10	ICD-9/ICD-10	0.11%	
					1999–2001	10	ICD-10	0.17%	
					2002–2004	15	ICD-10	0.21%	
					1990–1992	15	ICD-9	0.083%	
					1993–1995		ICD-9	0.18%	
					1996-1998		ICD-9/ICD-10	0.31%	
					1999-2001		ICD-10	0.43%	
					1990-1992		ICD-9	0.15%	
					1993–1995		ICD-9	0.31%	
					1996-1998		ICD-9/ICD-10	0.47%	
					1999-2001		ICD-10	0.68%	
					1990-1992		ICD-9	0.51%	
					1993-1995		ICD-9	0.85%	
Finland	1990–2007	Atladottir, Gyllenberg, Langridge, Sandin, Hansen, Leonard, Gissler, Reichenberg, Schendel, Bourke, Hultman, Grice, Buxbaum & Parner (2015)[13]	Official registry	Nationwide	1990-1992	5	ICD-9	0.10%	N/A
					1993-1995	5	ICD-9	0.11%	
					1996-1998	5	ICD-10	0.13%	
					1999-2001	5	ICD-10	0.16%	
					2002–2004	5	ICD-10	0.18%	
					2005-2007	5	ICD-10	0.26%	
					1990-1992	8	ICD-9	0.22%	
					1993-1995	8	ICD-9	0.30%	
					1996-1998	8	ICD-10	0.32%	
					1999-2001	8	ICD-10	0.36%	
					2002–2004	8	ICD-10	0.52%	
					1990-1992	10	ICD-9	0.31%	
					1993-1995	10	ICD-9	0.45%	
					1996-1998	10	ICD-10	0.47%	
					1999-2001	10	ICD-10	0.60%	
					1990-1992	15	ICD-9	0.56%	
					1993-1995	15	ICD-9	0.83%	
					1996-1998	15	ICD-10	1.01%	
					1990-1992	22	ICD-9	0.77%	
	2015	Delobel-Ayoub, Saemundsen, Gissler, Ego, Moilanen, Ebeling, Rafnsson, Klapouszczak, Thorsteinsson, Arnaldsdóttir, Roge, Arnaud & Schendel (2020)[35]	Official registry	Nationwide	2006	9	ICD-10	0.86%	82% male
					2007	8	ICD-10	0.77%	77% male
					2008	7	ICD-10	0.65%	79% male
Iceland	2009	Saemundsen, Magnússon, Georgsdóttir, Egilsson & Rafnsson (2013)[40]	Official registry	Nationwide	1994–1998	11–15	ICD-10/DSM-4	1.2%	74% male
	2015	Delobel-Ayoub, Saemundsen, Gissler, Ego, Moilanen, Ebeling, Rafnsson, Klapouszczak, Thorsteinsson, Arnaldsdóttir, Roge, Arnaud & Schendel (2020)[35]	Official registry	Nationwide	2006	9	ICD-10	2.51%	79% male
					2007	8	ICD-10	3.13%	82% male
					2008	7	ICD-10	2.40%	84% male

address the central research question of the current study and to be able to compare prevalence data from all seven countries it was necessary to lessen the criteria of national or official register data to obtain information about ASD prevalence for the Faroe Islands and Greenland.

Two studies for the Faroe Islands were identified and met all inclusion and exclusion criteria except for the criterion specifying that the data source should be a national or official register. In lack of national guidelines or registers for obtaining information about prevalence the research group applied a pragmatic approach. The first study conducted by Ellefsen et al[42] implemented a search procedure that started with one of the authors making radio and television appearance to spread awareness about ASD and the prevalence study. The same author gave open lectures about ASD in 2000 and 2002, where parents with children facing challenges showed up and listened. During these lectures, parents were encouraged to contact psychologists if they suspected their child of having ASD. Moreover, the researchers contacted and visited all 65 schools in the Faroe Islands and lectured all teachers with more than 10 students about ASD, while smaller schools with fewer than 10 students were contacted over the phone.

In the phone conversations between one of the authors and a given teacher, they discussed each student's potential signs of ASD.[42] Following this, a screening took place for those students showing signs of ASD which included the *Autism Spectrum Screening Questionnaire* (ASSQ). This screening identified 43 children and 41 parents that participated in further assessment and DISCO-10-interviews. A total of 41 children were included in the findings of the Ellefsen et al[42] study. The second study, conducted by Kočovská et al,[43] consisted of a follow-up population study based on the work of Ellefsen et al.[42] In 2009, the authors used a similar procedure to the one used in Ellefsen et al,[42] where they appeared on TV, radio and newspapers, alongside public lectures, etc. All children identified with ASD in 2002 and included in the Ellefsen et al[42] study were also invited to the follow-up. Furthermore, all hospital doctors, teachers, and psychologist were encouraged to refer cases with ASD or with a suspicion of ASD to the authors. The screening process for this study involved DISCO-11 interviews and the *Autism Diagnostic Observation Schedule* (ADOS). A total of 55 individuals from the same age cohort as the participants in the Ellefsen et al[42] study were identified as having ASD and were included in the final results of the Kočovská et al,[43] prevalence study. As illustrated in Table 2 results from the data collected in 2007 indicated at prevalence of 0.56% for children aged 7 to 16 years and 0.94% for the data collected in 2009 from young persons aged 15–24 years. There was a descriptive decrease in gender ratio for males showing more females receiving an ASD diagnosis in the follow-up study (from 92% to 73%). The balance of 73% males is aligned with what is reported by other Nordic countries, and the decrease could be due to a combination of age or/and changes in diagnostic tools.

Regarding Greenland we searched information on prevalence from grey literature, but without success. Following this, the next step was through contact with local organizations and contact with relevant individuals who could possibly provide an estimate of ASD prevalence in Greenland. A member of the autism association in Greenland (Autisme Foreningen Kalaallit Nunaat) confirmed on October 2023 that there are no ASD prevalence figures for Greenland. It was, however, assumed that the ASD prevalence figure was around 3–5% of the population, drawing parallels with corresponding figures for Denmark. However, this estimated prevalence figure differs greatly from the latest prevalence figures discovered for Denmark, which range closer to 0.98–1.47% for 7–9-year-olds.[35]

ASD Prevalence Across Age Groups

To be able to compare the prevalence figures presented in Tables 1 and 2, we created Table 3 to illustrate age-specific prevalence data for the five countries where national or official register-based prevalence figures were identified. This analyses allowed to examine more detailed descriptive comparisons between Nordic countries.

The data available for age groups were divided into the following respective four groups: 0–6, 7–12, 13–18 and 18+ year-olds, and included data from the latest prevalence studies. Across countries prevalence for the age group 0–6 ranged from 0.01% to 0.76%, the age group 7–12 ranged from 0.22% to 3.13%, the age group 13–18 ranged from 0.51% to 1.6%, and the 18+ age group ranged from 0.15% to 2.07%. This result indicates that the highest percentage of ASD prevalence was observed in the groups of children aged 7–12-years. This age group is also the most frequently reported age in the ASD prevalence studies included. According to Fombonne et al,[18] the emphasis of prevalence surveys generally targeting children aged 6–10 is expectable, as diagnosis at this age can more easily be verified compared to

Table 2 Nationwide Studies on ASD Prevalence Shown in per Hundred (%) for the Faroe Islands

Country	Data Year	Study	Geographic Level	Birth Year	Age	Diagnostic System	Prevalence %	Gender
Faroe Islands	2002	Ellefsen, Kampmann, Billstedt, Gillberg & Gillberg (2007)[42]	Nationwide	1985–1994	7–16	ICD-10/DSM-4	0.56%	92% male
	2009	Kočovská, Biskupstø, Gillberg, Ellefsen, Kampmann, Stora, Billstedt & Gillberg (2012)[43]	Nationwide	1985–1994	15–24	ICD-10/DSM-4	0.94%	73% male

younger ages. Moreover, the onset of awareness is often when children start school because difficulties with adaptive behaviour and learning often occur with the transition from preschool to school, where new and more complex demands arise.[18]

Norway appears to have the lowest ASD prevalence figures. However, as mentioned earlier, the most recent nationwide study on ASD prevalence in Norway by Özerk & Cardinal[38] suggests a prevalence of 0.18% for 1–5-year-olds born in 2011 and 0.41% for 6–16-year-olds born in 2000, contrasting with earlier studies that reported figures closer to 0.6–0.76%. The exclusion of earlier studies from Norway in our analyses may contribute to a misleading portrayal of ASD prevalence in Norway.

In Figure 2 we depicted the prevalence of three new age groups (5-, 10- and 15-year-olds) across different cohorts for Denmark, Sweden and Finland according to the study by Atladottir et al (2015). The figure shows increases in prevalence within each country and for all three age groups. However, the increase for the preschool group of five-year-olds was less compared to the increase in the two older age-groups.

Discussion

The current systematic review sets out to investigate the prevalence of ASD in Nordic and Scandinavian countries. Results showed that the answer to this question is quite complex, and the reasons for this are addressed in our discussion. Furthermore, the discussion will explore similarities and differences among the Nordic countries. Finally, the absence of prevalence studies in Greenland and explanations of this will be discussed.

First, many studies report on prevalence based on different diagnostic subgroups, which led the necessity of excluding several subgroups in our analyse, eg prevalence for individuals with ASD that have comorbid intellectual disabilities. We identified a total of 13 studies; however, only 11 reported prevalence based on national registers or official registries, and this accounted for five of the seven countries included in our review. Overall, the results confirmed an observed trend of a descriptive rising ASD prevalence over time across all five countries, which can be explained by several factors. According to Fombonne,[18] there are three explanations for the rising prevalence, and these are 1) a broadening of the concept of autism, 2) increased awareness of autism, and 3) improved detection and earlier diagnosis. These three factors will be elaborated in the following. Subsequently, the impact of data source, assessment, and diagnostic categorization on the increasing prevalence over time will be discussed.

Plausible Explanations for Descriptive Increases in Prevalence of ASD

The first explanation for the increasing ASD prevalence is the broadening of the concept of autism. The clinical understanding of ASD has changed from being a narrowly defined categorical diagnosis, to now being defined as a spectrum. This implies fewer individuals may be excluded from receiving a diagnosis, supporting the perspectives in ICD-11 which recognizes ASD as a heterogeneous diagnosis.[10] This shift may also have influenced improved recognition of ASD in adults, leading to a rise in ASD prevalence[28] and late diagnosed persons.

Researchers argue[18,23] the descriptive rising ASD prevalence is due to increased awareness. For example, awareness in parents as well as in the public, but also globally. The third explanation can be linked to the improved detection and earlier diagnosis, particularly in high-income countries (like the Scandinavian and Nordic countries) that have

Table 3 Nationwide Studies on ASD Prevalence Shown in per Hundred (%) for Denmark, Norway, Sweden, Finland, Iceland & the Faroe Islands Divided per Age Groups

	Denmark					**Norway**				**Sweden**		**Finland**		**Iceland**		**Faroe Islands**	
Study	Parner et al (2011)[32]	Parner et al (2008)[33]	Atladottir et al (2015)[13]	Hansen et al (2015)[34]	Delobel-Ayoub et al (2020)[35]	Surén et al (2013)[36]	Surén et al (2019)[41]	Kiselev et al (2020)[37]	Özerk & Cardinal (2020)[38]	Lundström et al (2015)[39]	Atladottir et al (2015)13	Atladottir et al (2015)[13]	Delobel-Ayoub et al (2020)[35]	Saemundsen et al (2009)[40]	Delobel-Ayoub et al (2020)[35]	Ellefsen et al (2007)[42]	Kočovská et al (2012)[43]
Cohort	2004	2006	2011	2011	2015	2008–2011	2016	2014	2016	2002	1990–2007	1990–2007	2015	2009	2015	2002	2009
Age																	
0–6 years	0.40%	N/A	0.09–0.36%	0.01%	N/A	N/A	0.7%[d]	0.76%[e]		N/A	0.049–0.21%	0.10–0.26%	N/A	N/A	N/A	N/A	N/A
7–12 years	0.55–0.66%	0.62–0.74%	0.26–1.1%	0.98%	0.98–1.47%	0.60%[c]	N/A	N/A		0.23–0.60%	0.83–0.68%	0.22–0.60%	0.65–0.86%	N/A	2.40–3.13%	0.56%[g]	N/A
13–18 years	N/A	0.82%	0.73–1.6%	0.98%[b]	N/A	N/A	N/A	N/A		N/A	0.51–0.85%	0.56–0.60%	N/A	1,2%[f]	N/A	N/A	0.94%[h]
18+ years	N/A	N/A	1.09%	N/A	0.15–2.07%	N/A	N/A	N/A		N/A	N/A	0.77%	N/A	N/A	N/A	N/A	0.94%

Note: This table demonstrates the latest prevalence figures for each study. [a]The study's youngest birth cohort from 1990–1991 is included, [b]Age 6–21 years, [c]Age 6–12 years, [d]Age 2–8 years, [e]Age 2–7 years, [f]Age 11–15 years, [g]Age 7–16 years, [h]Age 15–24 years.

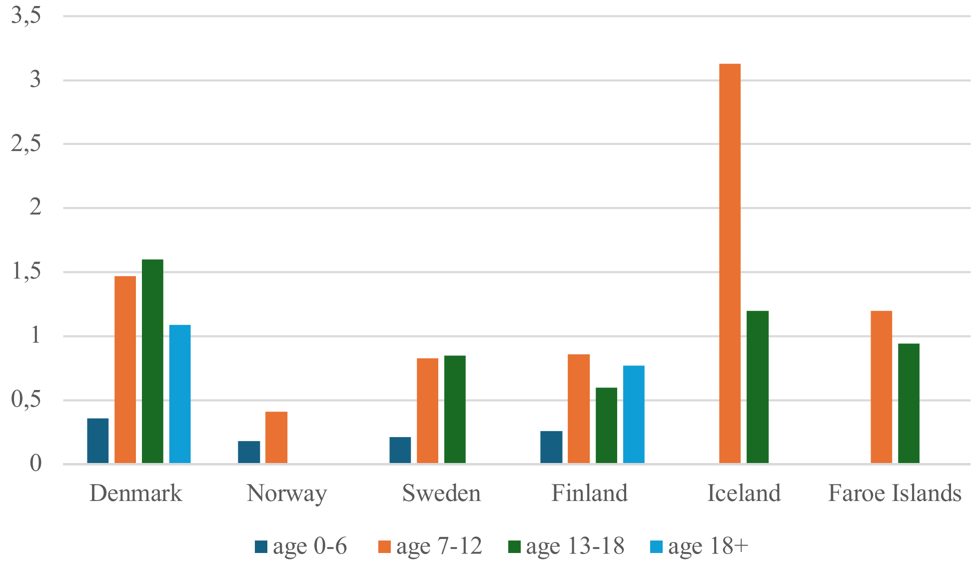

Figure 2 ASD prevalence for Denmark, Norway, Sweden, Finland, Iceland, and Faroe Islands shown in per hundred (%) and divided into four age groups.

implemented policies to facilitate this improvement. These policies are likely contributing to better identification of ASD cases, and thereby impacting prevalence rates.[28] For example, in Denmark children that are suspected of having a mental disorder are referred by general practitioners or school psychologists to a child psychiatric ward. The wards oversee the diagnosing based on assessments performed by multi-disciplinary teams. All assessments and diagnostic evaluations are free of charge; however, recently, there are long waiting lists resulting in more and more parents approaching private clinics for a diagnostic evaluation through private insurances.

Additionally, it is also relevant to investigate how access to different data sources might affect prevalence figures.[44] The 11 studies identified in our systematic searches were all from national registries or official registries. This inclusion criterion was based on the knowledge that the method ensures a certain quality and basis for comparison. In Denmark, the national electronic registers contain data from 1969 and onwards for every psychiatric admission, thereby containing information on all patient contact with psychiatry ward.[14] National registers are therefore also often considered as the primary source of valid and reliable data for gathering prevalence figures. The two studies additionally added to the analyses in order to include data for the Faroe Islands relied on a more pragmatic data collection method are hence considered less valid and reliable. Nevertheless, both studies contribute to valuable knowledge about ASD in the Faroe Islands, providing an indication of ASD prevalence in an unrepresented country.

Similarities and Differences Among the Nordic Countries

The Nordic countries are generally perceived as nations with good public policies, good public administration, and are perceived in the world to have a high level of trust in government. Examining the similarities and differences among the Nordic countries provides insight into the finding that national registers of ASD prevalence figures do not exist for the Faroe Islands and Greenland. Firstly, it is important to note that Iceland, the Faroe Islands and Greenland are all countries with small population sizes compared to the other Nordic countries. Iceland had a population of 390.000 in 2023,[45] the Faroe Islands had 53.652 inhabitants in 2022,[46] and Greenland had 56.609 inhabitants in 2023.[47] This is in contrast with the larger population in Finland with 5.548.241 in 2022,[48] Denmark with 5.959.464 in 2023,[49] Norway with 5.488.984 in 2023,[50] and Sweden with a population of 10.521.556 in 2023.[51]

Prevalence estimates are affected by sociodemographic aspects. All Nordic countries have healthcare systems that are mainly funded through taxation (Health management). Especially, the health care systems in the Scandinavian countries consisting of Denmark, Norway and Sweden are very similar.[52] This means every citizen has equal access to health services. It is relevant here to mention that the Faroe Islands and Greenland are both in a commonwealth with Denmark, but both have an extensive degree of self-government.[53] In the case of the Faroe Islands, the management and administration of healthcare in the Faroe Islands are handled by the country itself, but the authorization of healthcare professionals is regulated by Denmark. This is also the case for Greenland where the healthcare system is dependent on recruitment of professionals from Denmark.[54] Since the transfer of healthcare authority to Greenland in 1992, Denmark no longer holds responsible for the healthcare of Greenlandic citizens. However, citizens from Greenland requiring more extensive examination and treatment than what is available in Greenland are referred to Denmark for services.[54]

For some Nordic countries, access to healthcare services is more geographically challenging than others. Despite shared values and similar healthcare services, inequalities arise due to geographical factors, particularly in small, populated areas with limited infrastructure.[55] Long distances to healthcare services in, eg, Iceland is a challenge, where the provision of specialist services is almost exclusively located in Reykjavik and neighbouring communities.[56] Geographical distances are also a challenge in the Faroe Islands, as the country consists of 18 different islands[43] and 16 cities with 60 rural areas[57] resulting in logistic difficulties. Finally, Greenland is especially geographically challenged as it consists of 75 independent islands that rely on transportation by use of planes, helicopters, ships, dinghies, or dogsleds due to the lack of infrastructure.[58] For many citizens in Iceland, the Faroe Islands and Greenland, air services are a necessary to receive health services, and due to their high cost, this factor contributes to inequality between the Nordic countries.[59] Consequentially, citizens in Greenland must maintain insurance coverage for transportation[60] to have access to health services. Together these factors may affect individuals' access to assessment and ultimately affect ASD prevalence figures.

The Absence of ASD Prevalence Studies in Greenland

The absence of ASD prevalence studies for Greenland may be comparable to what has been reported for other first nations or subnationss eg, First Nations in Canada,[61] Aboriginals in Australia,[62] and the Māori in New Zealand.[63]

Turning to the history of Greenland, it is relevant to note that Greenland was colonized by Denmark in 1721[64] and as mentioned was first handed over the responsibility for its own healthcare system in 1992.[54] Awareness of ASD may therefore be seen as a recent area of focus in Greenland, and especially in politics, where it has only recently been discussed since 2016–2017 (personal communication with Autisme Foreningen Kalaallit Nunaat, Greenland).

Regarding the structure of the Greenlandic healthcare system, the absence of ASD prevalence figures could also be attributed to the existence of two parallel systems (personal communication Autisme Foreningen Kalaallit Nunaat, Greenland). In Greenland, some individuals receive an ASD diagnosis from the health service in Greenland, while others receive the diagnosis through one of the municipalities. These two systems operate independently and do not collaborate, which may be an obstacle for the collection of nationwide and register data. This structural challenge is further validated through qualitative interviews of barriers to psychological services in Greenland. Four barriers were identified 1) deficiencies in case processing and visitation, 2) a shortage of staff, 3) lack of collaboration between authorities and support services, and 4) a lack of cooperation among the police, school, and health sectors.[65]

An additional potential explanation for the missing prevalence data may be related to the taboo of invisible disabilities in the Greenland culture (personal communication Autisme Foreningen Kalaallit Nunaat, Greenland). In a scoping review investigating stigma in the Nordic countries results showed that attitudes towards mental illnesses are influenced by three factors which are 1) cultural context, 2) knowledge and 3) personal contact with people with mental illnesses.[66] This supports the suggestion that lack of ASD prevalence data in Greenland may be affected by Greenlandic attitudes towards mental health problems or/and from a lack of awareness of ASD.

Expanding on the cultural context influencing knowledge of prevalence, a recent study by Atherton et al[67] explored the importance of culture in understanding the ASD diagnosis. The authors discovered that the perception of an autistic individual in the neurotypical world depends on the cultural costumes and values in the respective country. The study further revealed that certain ASD symptomatologies are more widely accepted or even integrated into certain cultures or communities than in others. Greenland stems from a hunting culture, and hunting is still an important part of the culture identity for many Greenlanders[56] therefore the healthcare system should consider adopting a more Greenlandic psychology. Additionally, considerations must be given to the origins of diagnostic categories and theories, including where they are formulated. Most psychological theories today are formulated in English-speaking countries and are then widely accepted as globally general theories.[56] However, these theories may ignore cultural variations. When assessing ASD symptomatology, cultural considerations should be considered, since the definition of "normal" may vary across cultures. Furthermore, there exists variation in communication styles, and expectations for, eg, eye contact and physical touch in different cultures.[68] It is therefore crucial to keep this in mind to avoid over- or under identification of ASD.

The autism association in Greenland is actively engaged in this effort and determined to share knowledge and educate Greenlanders about ASD through organized public lectures and conferences. Implementing such activities may contribute to reducing negative attitudes towards mental illnesses in general. A progression seems underway in Greenland regarding the understanding of ASD and the impact it may have on people.

Strengths, Limitations and Future Research

Being the first systematic literature review encompassing all seven Nordic countries, this study provides crucial insights and enables preliminary comparisons of ASD prevalence figures between the Nordic countries. As for all studies, some limitations were present in our study. Firstly, due to the large variation in how different studies report on prevalence, when reporting on specific subgroups of ASD we only included studies that reported prevalence across subgroups and hence our results reflect prevalence in ASD as an umbrella group. A second limitation is that the second author was solely responsible for the initial stage of the screening process; therefore, it was not possible to carry out inter-coder reliability.

Future research within this field should seek to include citywide and countywide studies, thereby introducing a broader range of prevalence figures. The findings in this review highlight a need for further investigation of ASD prevalence in Greenland and the Faroe Islands. In the absence of ASD prevalence data in Greenland, upcoming studies aiming to address this gap in the literature could benefit from adopting methodologies employed by Ellefsen et al[42] and Kočovská et al[43] in their studies conducted in the Faroe Islands.

Given the heterogeneity of ASD, screening and/or diagnostic tools have been revised in part to generate validated culturally appropriate tools.[23] The most common standardised methods for assessment, and thereby evaluations of autism symptoms, the *golden standards* are the *Autism Diagnostic Interview-Revised* (ADI-R) and ADOS.[69] ADI-R is a parental interview where the parents or caregivers identify symptoms of ASD, and ADOS is based on interactive play and conversation between the child and a professional and evaluated through subjective coding of certain behaviours. Here, The ADOS provides information that is important for assessing the child's social interaction, communication and behaviour.[41]

The implementation of gold standards for ASD assessment was intended to lead to a greater degree of comparability between practitioners and researchers[70] and thereby also to the possibility of comparing ASD studies across cultures.[71] In order to obtain valid and cultural fair knowledge about ASD prevalence in non-western countries such as Greenland, it is important to evaluate whether some aspects of the ADI-R and ADOS might be biased to capture child-adult interactions that represent those in WEIRD countries. ADOS-2 is the newest version and is internationally a widely established assessment tool resulting in 23 published versions of ADOS-2 around the world.[68]

Furthermore, as recently pointed out by Rea et al (2023), research suggests ADOS-2 may underdiagnose girls, resulting in a greater number of males being diagnosed with ASD diagnosis.[68] As mentioned, camouflaging is common among females with ASD and may bias results of assessments based on ADOS-2 where females find it easier to imitate the ADOS-2 clinician as it is often cisgender females who carry out the assessment. This aspect should also be taken into account in aiming for more gender-fair assessments and treatments of ASD.

Conclusion

The systematic literature review included 13 studies of the prevalence of ASD across all the Nordic countries which were based on national or official registers as well as two nationwide studies from the Faroe Islands. The majority of ASD prevalence studies reported predominantly in the age group of 7–12-year-olds. For this age group, the most recent prevalence figures in Denmark ranged from 0.26% to 1.47%, in Norway prevalence was 0.60%, in Sweden it ranged from 0.23% to 0.68%, in Finland it varied from 0.22% to 0.86%, and in Iceland, it ranged between 2.40% and 3.13%. In the studies that included gender ratio, findings indicated a percentage of 73% or higher in males, signifying a higher diagnosis rate in males compared to females. For the Faroe Islands, the two available studies provided ASD prevalence figures ranging from 0.56% to 0.94%. Results showed a descriptive rising trend in prevalence over time – especially for the school age children.

The rising ASD prevalence rates reported in our results may be impacted by a broadening of the concept of ASD, increased awareness of the diagnosis, improved detection methods, and earlier diagnosis. Different approaches to assessment might also contribute to varying prevalence rates, with particular focus on ADOS-2, which, however, might potentially underdiagnose girls with ASD. Moreover, when comparing prevalence rates across countries, it is crucial to consider both the similarities and differences among them. In the case of the Nordic countries, all countries are high-income economies, which is fundamental for their similar high level of health service opportunities.

No ASD prevalence studies were identified for Greenland. According to a member of the autism association in Greenland Association of Autism, Kalaallit Nunaat, the absence of ASD prevalence data in Greenland may be attributed to the parallel operation of two systems. The lack of collaboration between the two systems challenges possibilities of data gathering of prevalence figures. The absence of ASD prevalence figures in Greenland can therefore be explained by structural challenges, and a potential lack of awareness leading to stigmatization of individuals with ASD. Moreover, it is crucial to acknowledge the impact of extreme weather conditions and logistical challenges in Greenland, which undoubtedly contribute to the gap in the literature.

Varying understandings of ASD, including awareness and perceptions of ASD symptomatology, can differ from country to country. This aspect is particularly relevant for a country such as Greenland, where a hunter-identity remains relevant. Historical factors such as colonization and delayed recognition of mental illnesses in Greenland could also potentially influence ASD awareness and research conducted in the country.

Disclosure

The authors do not have any conflicts of interest to report for this work.

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