

Autism in Children and Adolescents with Epilepsy – Scoping Review and Adaptation of Clinical Practice Guidelines for Recognition, Referral and Diagnosis: A Report of the ILAE Task Force on Paediatric Psychiatric Issues

Colin Reilly^{1,2,3}

Jay Salpekar^{4,5}

Francesco Brigo⁶

Eliza Honybun^{7,8}

Charlotte Tye⁹

Nicola Speechio^{10, 11}

Laura M Guilhoto^{12,13}

Rohit Shankar^{14,15}

Kirsten A Donald^{16,17}

Mary Lou Smith¹⁸

Emma Dalrymple¹⁹

Chahnez Charfi Triki²⁰

Stephane Auvin^{21,22,23}

Kette Valente^{13,24}

Affiliations

¹ Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK.

²Dept. of Pediatrics, Institute of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden.

³Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden

⁴Kennedy Krieger Institute, Baltimore, USA

⁵Johns Hopkins University School of Medicine, Baltimore, USA

⁶Innovation, Research and Teaching Service, Teaching Hospital of the Paracelsus Medical Private University (PMU), Azienda Sanitaria dell'Alto Adige, Bolzano-Bozen, Italy

⁷Epilepsy Research Centre, Department of Medicine (Austin Health), The University of Melbourne, Australia.

⁸Department of Clinical Neuropsychology, Austin Health, Melbourne, Australia.

⁹Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London

¹⁰Neurology, Epilepsy and Movement Disorders, Full member of European Reference Network EpiCARE Bambino Gesù Children's Hospital, IRCCS, Rome, Italy

¹¹University Hospitals KU Leuven, Belgium

¹²Epilepsy Unit, Department of Neurology and Neurosurgery, Federal University of São Paulo, São Paulo-SP, Brazil

¹³ Hospital Universitário, University of São Paulo, São Paulo, Brazil

¹⁴Peninsula School of Medicine, University of Plymouth, Plymouth UK

¹⁵ Cornwall Partnership NHS Foundation Trust, Truro UK

¹⁶Department of Paediatrics and Child Health, Red Cross War Memorial Children's Hospital and University of Cape Town, Cape Town, South Africa,

¹⁷Neuroscience Institute, University of Cape Town, Cape Town, South Africa

¹⁸Department of Psychology, University of Toronto Mississauga and Neurosciences and Mental Health Program, The Hospital for Sick Children, Toronto ON Canada

¹⁹Parent to a child with epilepsy and autism

²⁰Child Neurology Department, LR19ES15, Sfax Medical School, University of Sfax, Sfax, Tunisia

²¹Université Paris Cité, INSERM NeuroDiderot, Paris, France

²²APHP, Robert Debré University Hospital, Pediatric Neurology Department, CRMR epilepsies rares, EpiCare member, Paris, France

²³Institut Universitaire de France, (IUF), Paris, France

²⁴ Department of Neurology and Neurosurgery, Federal University of São Paulo, São Paulo, Brazil

Correspondence to: Colin Reilly, Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK. creilly@youngepilepsy.org.uk 01342 832243

Keywords: autism, epilepsy, children, guidelines

Number of figures: 2

Number of tables: 3

Number of references: 39

Short title: Autism in children with epilepsy

Abstract

There are currently no specific Clinical Practice Guidelines (CPGs) for recognition, referral and diagnosis of autism in children with epilepsy. The members of the International League Against Epilepsy (ILAE) Task Force on Pediatric Psychiatric Issues conducted a scoping review adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) standards. The ADAPTE process was used including a Delphi method to adopt/adapt existing guidelines for the referral, assessment, and communication of the diagnosis of autism in children, for use in children with epilepsy. A systematic search found 19 CPGs and these were critically appraised using the Appraisal of Guidelines for Research and Evaluation (AGREE II) instrument, which assesses guideline quality across domains such as rigor, clarity, and applicability. The NICE guideline, *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*, received the highest appraisal and was selected as the source for adoption/adaptation. Sixty-three recommendations were successfully adopted/adapted for children with epilepsy. The key recommendations include: (1) Clear local pathways overseen by a lead professional/clinician, ensuring referrals are directed to a multidisciplinary team with the necessary expertise; (2) Autism should be suspected when developmental or behavioral concerns are present. Any loss of skills (language, social, motor) warrants immediate referral to the local autism team for assessment; (3) Assessment should begin within three months of referral, include information for multiple sources and differential diagnosis, and follow DSM-5 or ICD-11 criteria. Caution regarding diagnosis is required in children with epilepsy under 24 months or with developmental levels under 24 months; (4) Diagnoses must be communicated sensitively, with follow-up discussions, sharing information with medical/educational/social services, and tailored guidance for families, including connection to autism support organizations

and planning for transition to adult services. The assessment of children with epilepsy for autism requires access to clear clinical pathways and a trained multidisciplinary team.

Keywords: ASD; autism; guidelines; ADAPTE; diagnosis; epilepsy; child; adolescent.

Key Points

- Clear local pathways overseen by a lead professional, ensuring referrals are directed to a multidisciplinary team with the necessary expertise is recommended.
- Autism should be suspected when significant developmental or behavioral concerns are present.
- Any loss of skills (language, social, motor) warrants referral for autism assessment.
- Assessment should begin within 3 months of referral, and include multiple information sources, consideration of differential diagnoses, according to DSM-5 or ICD-11 criteria.
- Diagnostic uncertainty may exist regarding autism in children with epilepsy under 24 months of age or with developmental levels below 18 months of age.

Introduction

Autism Spectrum Disorder (hereafter ‘autism’) is one of the most common co-occurring neuropsychiatric conditions in children with epilepsy¹ and the prevalence of autism in children with epilepsy is much higher than in the general pediatric population². In a systematic review of 74 studies, the median overall period prevalence of autism in people with epilepsy was 9%³, much higher than the reported prevalence in the general population. Co-occurring autism and epilepsy in individuals with autism is associated with lower quality of life and worse social outcomes⁴. Individuals with both autism and epilepsy are at greater risk for deleterious health outcomes compared with those with epilepsy alone, including in-hospital mortality⁵.

Clinical practice guidelines (CPGs) play a crucial role in improving patient outcomes by reducing variability in care, supporting clinical decision-making, enhancing quality improvement, and facilitating collaboration among healthcare providers^{6,7}. Adaptation of guidelines requires a systematic approach to enable adjustment of such guidelines to be applicable in broader contexts^{8,9}. In addition to modification, existing guidelines may be adopted without modification if it is felt that they are relevant for the particular target group.

There are currently no accepted recommendations for the screening and assessment of autism in children with epilepsy¹⁰. Additionally, it is important to note that screening is only one part of the assessment process and comprehensive guidance is needed regarding recognition of autism in children with epilepsy which includes screening as well as referral and diagnosis (including communication of diagnosis and follow-up). The aim of this work was to conduct a scoping review of CPGs for the recognition, referral and

diagnosis of autism in children can to adapt/adopt the highest-ranking guideline for children with epilepsy.

Methods

The ADAPTE process (or framework) offers a systematic and practical approach for adopting and/or adapting existing guidelines for use in different settings¹¹. It is designed to ensure that the adopted/adapted recommendations not only address specific health questions relevant to the local context but that they also align with the needs, priorities, policies, and available resources of the targeted setting. The ADAPTE process has been developed to support a range of users and organizations, including guideline developers, healthcare providers, and groups operating with varying levels of resources. The health question of the ADAPTE process is shown in Table 1.

Table 1: Health question of the ADAPTE process – recognition, referral and diagnosis of autism in children and adolescents with epilepsy

Population (P)	Children and adolescents (0-17 years) with epilepsy.
Intervention (I)	Adoption/adaptation of existing CPG recommendations for Autism Spectrum Disorder/Autism recognition, referral, and diagnosis tailored to the children and adolescents with epilepsy.
Professional (P)	Healthcare providers with responsibility for children with epilepsy.
Outcomes (O)	Feasibility and applicability of guideline recommendations in epilepsy care. Appropriateness of recognition, referral and diagnostic pathways (timeliness, accuracy, and sensitivity to epilepsy-specific features such as developmental regression and plateau).

	Key adapted recommendations (e.g., early referral, multidisciplinary team involvement, communication, and transition planning). OR Accurate and timely recognition and diagnosis of ASD; applicability and feasibility of adapted recommendations; improved referral pathways; better family guidance and support.
Health	Epilepsy clinics, pediatric neurology services, and multidisciplinary care settings across diverse international healthcare systems.

There are three phases in the ADAPTE framework as described below¹¹.

1. Set-up Phase

The set-up phase involves the creation of the working group and the expert panel. The working group consisted of members of the International League Against Epilepsy (ILAE) Pediatric Psychiatric Issues Task Force (CR (Pediatric Psychologist), JS (Pediatric Psychiatrist), EH (Pediatric Neuropsychologist), SA (Pediatric Neurologist), NS (Pediatric Neurologist), MLS (Pediatric Neuropsychologist), KV (Pediatric Neurologist), CT (Research Psychologist), KAD (Pediatric Neurologist) and one neurologist and methodologists from the ILAE Standard and Best Practice Council (FB, CCF). Two members of the ILAE Intellectual Disability Task Force (RS (Adult Neuropsychiatrist), LG (Pediatric Neurologist)) were invited and joined the working group given the high association between the occurrence of autism and Intellectual Disability in epilepsy. A caregiver (ED) of a young person with epilepsy and autism was involved in the writing of the manuscript. Disclosures of interest for each individual member are reported.

2. Adaptation

In the Adaptation Phase of ADAPTE, one critical step is to identify existing guidelines and assess their quality before deciding whether to adopt, adapt, or exclude their recommendations.

2.1 Scoping Review

The scoping review was registered on Open Science Framework ([OSF | Scoping Review of Clinical Practice Guidelines for Recognition, Referral and Diagnosis of Autism in Children](#)). The search for guidelines (from inception) was undertaken on 14th February 2024 and updated on 3rd November 2025 by a librarian with expertise in systematic reviews (VC). A comprehensive search strategy was undertaken to identify relevant guidelines (see supplement 1). Inclusion criteria were guidelines developed by established national or professional organizations that focused specifically on autism (including autism, Autism Spectrum Disorder, Asperger syndrome/disorder, Autistic Disorder, or Pervasive Developmental Disorder–Not Otherwise Specified), and addressed screening, assessment, or diagnosis in children aged 0–17 years. Guidelines addressing both children and adults were included only if child-specific recommendations could be clearly extracted. Exclusion criteria were guidelines developed by a single hospital, center, or regional or state body; opinion-based publications from individual authors or research groups; those focused on neurodevelopmental difficulties not specific to autism; guidelines addressing treatment or intervention rather than screening, assessment, or diagnosis; those focusing exclusively on adults aged 18 years or older; systematic reviews of guidelines; and studies examining adherence to autism spectrum disorder screening or assessment guidelines.

The full inclusion and exclusion criteria are in Supplement 2. In order to be as inclusive as possible and not miss relevant work we included some publications which did not explicitly use the word ‘Guidelines’ but instead used the word guidance, practice parameter or recommendations. Searches were run in: the National Guideline Clearinghouse, Guidelines International Network (GIN), Association of the Scientific Medical Societies in Germany (AWMF) Guidelines Register, International database of Grading of Recommendations Assessment, Development and Evaluation (GRADE) guidelines (BIGG), GRADE Evidence to Decisions (EtD) and Guidelines database, Emergency Care Research Institute (ECRI) Guidelines Trust, Making GRADE the Irresistible Choice (MAGIC) authoring and publication platform (MAGICapp), National Institute for Health and Care Excellence (NICE) Evidence database, the State Expert Center of the Ministry of Health of Ukraine registry of medical and technological documents, Turning Research Into Practice (TRIP) database, U.S. Preventive Services Task Force (USPSTF), Scottish Intercollegiate Guidelines Network (SIGN), World Health Organization (WHO) guideline database, Institute for Clinical Systems Improvement (ICSI), and New Zealand Ministry of Health guidelines. In addition, broader literature searches were conducted using Google Scholar and PubMed to capture relevant peer-reviewed evidence not indexed in guideline-specific The sources searched are in Supplement 1 and full searches are in Supplement 3. The Preferred Reporting Items for Systematic. The scoping review was reported according to the PRSIMA-Scoping Review reporting standards (PRISMA-ScR)¹² (see supplement 4)

Guidelines were screened independently by two reviewers (CR and JS) manually. After the screening stage, the reference lists of all guidelines included were handsearched to identify further relevant guidelines. Guidelines included in the final qualitative synthesis

were then ranked independently using the AGREE II¹³ checklist by two Task Force Members (CR and JS). All conflicts were resolved by consensus.

3. Finalization (Feedback)

In order to seek consensus on the adoption/adaption of guidelines from the top ranked guidelines for children with epilepsy we employed the Delphi method. The Delphi method is a multi-round survey process where experts answer questions anonymously, receive feedback, and then revise their responses until a level of agreement is reached¹⁴. The working group members went through each recommendation. Each recommendation was voted on via SurveyMonkey (an online web-based survey platform) and rated as ‘adopt’, ‘adapt’ or ‘reject’, based on the following scoring criteria:

1. Adopt the guidelines which have been endorsed by $\geq 80\%$ of respondents i.e. at least 80% selected ‘yes’ on the first round or second round
2. Adapt the guidelines which have a need to be adapted and re-vote, i.e. have not reached 80% ‘yes’ but there is 80% between ‘yes’ and ‘adapt’ on round 1
3. Reject the guidelines that do not reach 80% in ‘yes’ or ‘adapt’ on round 1

The last stage of the finalization stage of ADAPTE involves a review of recommendations and publishing the adopted recommendations on the ILAE website.

Results

Search Process and Voting Results

The flow chart in figure 1 shows the search and selection process for guidelines. After screening, 12 relevant guidelines were selected. After searching the references in these guidelines, a further seven relevant guidelines were found, and it is these 19 guidelines¹⁵⁻³³ that were selected for inclusion and for which AGREE-II ratings were obtained. The characteristics of the 19 guidelines are included in Table 2.

Table 2: Guidelines for Recognition, Referral and Diagnosis of autism in children included in the ADAPTE process

Year of Publication	Guideline name	Country of Origin	Organization/body responsible for Guideline
2024	Finnish Medical Society Duodecim, Finnish Association for Child Psychiatry, Finnish Adolescent Psychiatry Association, Finnish Association of Physicians for Intellectual Disabilities, Finnish Child Neurology Association, and Finnish Psychiatric Association working group. <i>Autism spectrum disorder: Current Care Guideline</i> . Helsinki: Duodecim; 2024.	Finland	Finnish Medical Society Duodecim, Finnish Association for Child Psychiatry, Finnish Adolescent Psychiatry Association, Finnish Association of Physicians for Intellectual Disabilities, Finnish Child Neurology Association, and Finnish Psychiatric Association working group
2024	Diagnosis and Assessment of Autism Spectrum Disorder in South Korea -Korean Practice Guideline for Autism Spectrum Disorder	South Korea	Ministry of Health and Welfare, Behavior and Development Center, and the Headquarter of the National Autism and Developmental Disorder Centers.

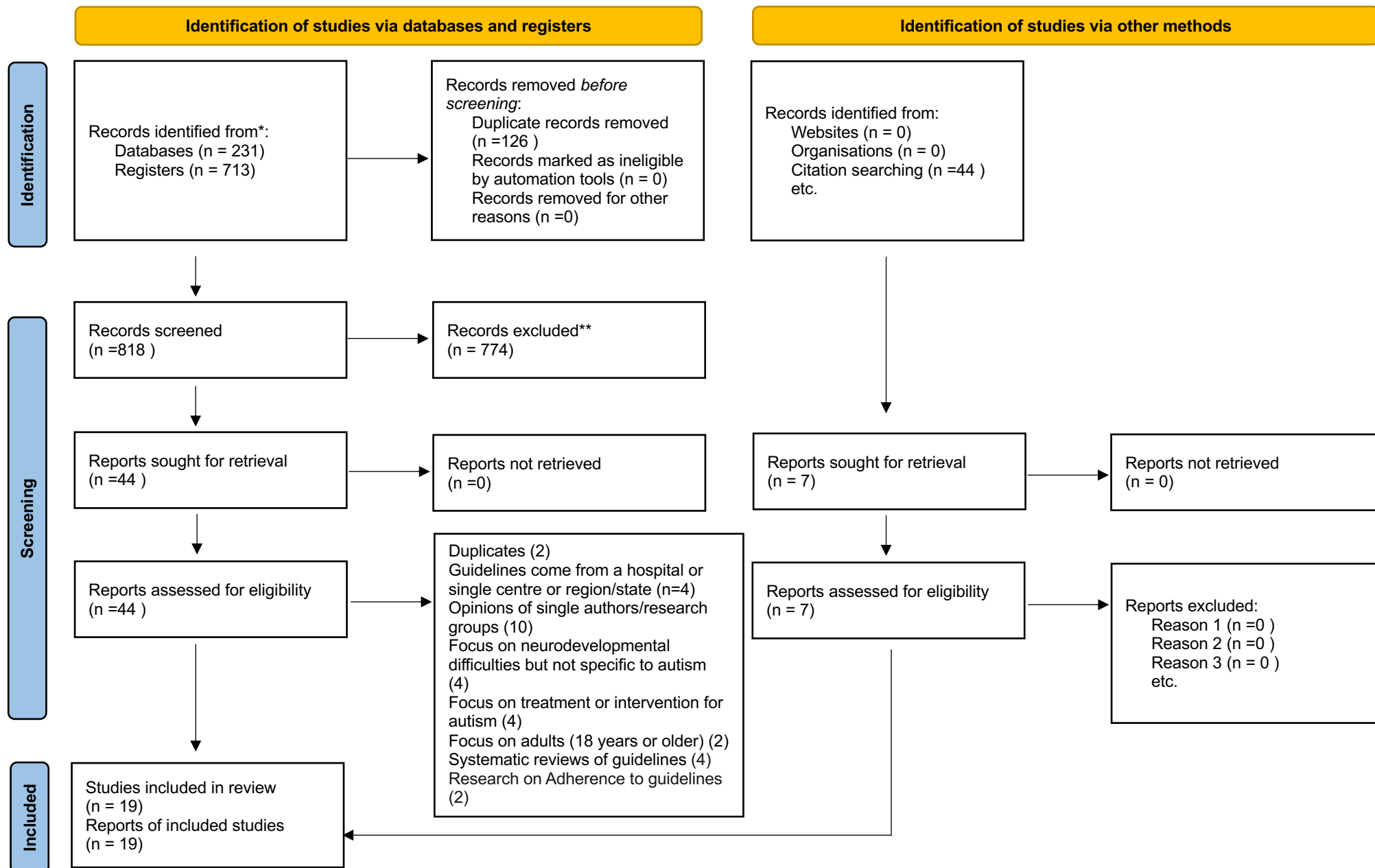
2023	Autism spectrum disorder in children and adolescents - clinical practice guidelines on autism spectrum disorder in children and adolescents	Singapore	College of Paediatrics and Child Health, Singapore
2022	Professional Practice Guidelines for the Assessment, Formulation, and Diagnosis of Autism in Children and Adolescents, 2nd Edition	Ireland	Psychological Society of Ireland
2022	Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau	New Zealand	Ministry of Disabled People and Ministry of Education
2021	ESCAP practice guidance for autism: a summary of evidence-based recommendations for diagnosis and treatment	Europe	European Society for Child and Adolescent Psychiatry (ESCAP)
2020	Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder	USA	American Academy of Child and Adolescent Psychiatry

2020	Identification, Evaluation, and Management of Children With Autism Spectrum Disorder - clinical report Guidance for the Clinician in Rendering Pediatric Care	USA	American Academy of Pediatrics
2019	Early detection for autism spectrum disorder in young children	Canada	Canadian Paediatric Society
2019	Standards of diagnostic assessment for autism spectrum disorder	Canada	Canadian Paediatric Society
2018	A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia	Australia	Autism CRC (Autism Cooperative Research Centre)
2018	Autism spectrum disorder: Warning signs, detection, diagnosis and assessment in children and adolescents. Clinical practice guidelines method	France	French National Authority for Health
2017	Autism spectrum disorder in under 19s: recognition, referral and diagnosis	UK	National Institute for Health and Care Excellence

2016	Autism spectrum disorders in childhood, adolescence and adulthood. Part 1: Diagnosis. Interdisciplinary S3 guideline.	Germany	German Society for Child and Adolescent Psychiatry, Psychosomatics and Psychotherapy German Society for Psychiatry and Psychotherapy, Psychosomatics and Neurology
2016	Screening for Autism Spectrum Disorder in Young Children US Preventive Services Task Force Recommendation Statement	USA	US Preventive Services Task Force
2016	Assessment, diagnosis and interventions for autism spectrum disorders: A national clinical guideline	Scotland/UK	Scottish Intercollegiate Guidelines Network
2010	Autism Spectrum Disorders in Pre-School Children -Clinical Practice Guideline	Singapore	Ministry of Health, Singapore
2008	Screening, Assessment and Diagnosis of Autism Spectrum Disorders in Young Children - Canadian Best Practice Guidelines	Canada	Miriam Guidelines
2000	Practice parameter: screening and diagnosis of autism	USA	American Academy of Neurology

			and the Child Neurology Society
--	--	--	---------------------------------

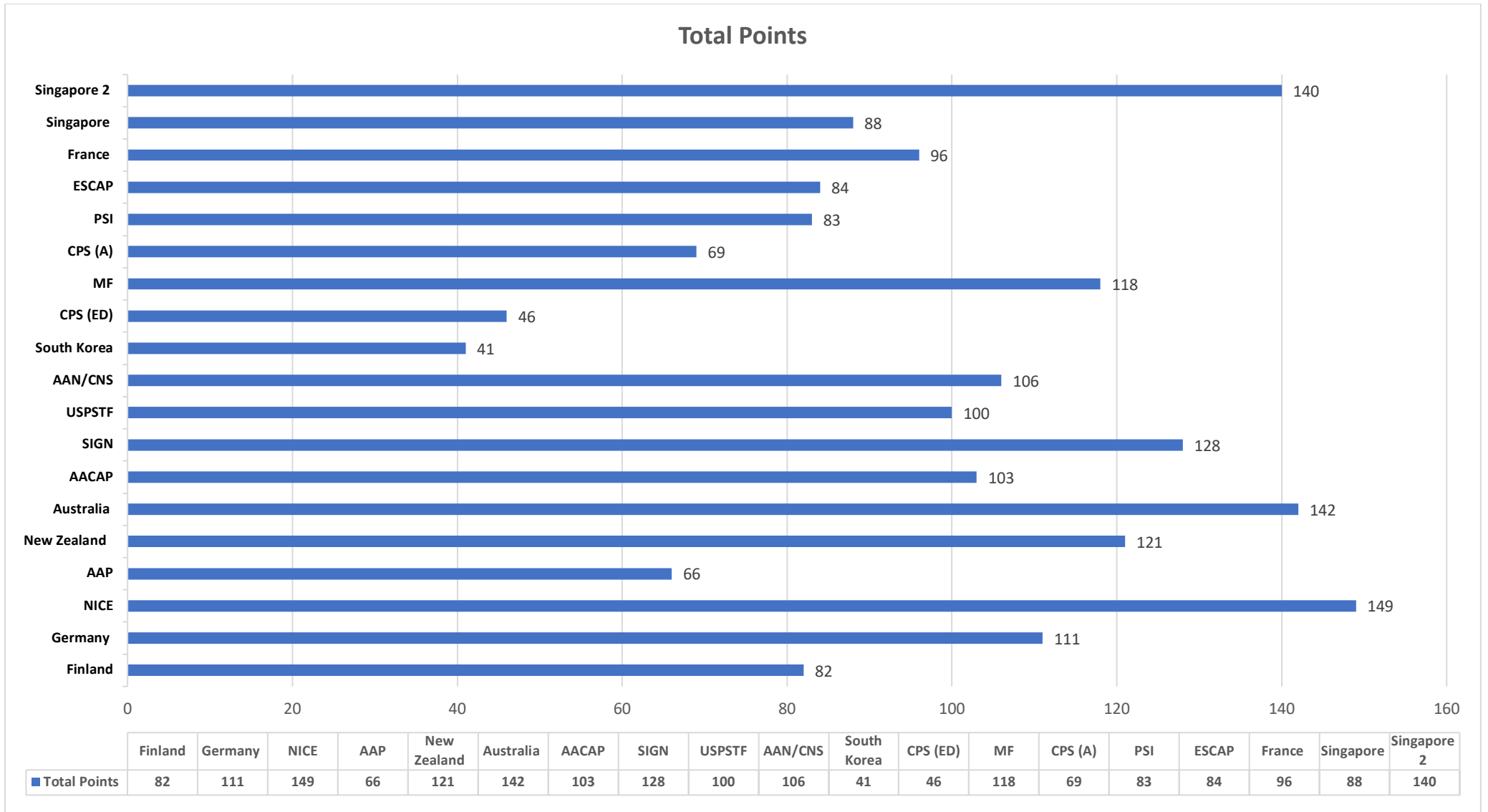
Figure 1: Search process for Clinical Practice Guidelines (CPGs) for assessing autism in children



AGREE-II Ratings

The results of the AGREE-II ratings are shown in Figure 2 and table 3. The guidelines with the best scores were National Institute for Health and Care Excellence (NICE) Guidance Autism Spectrum Disorder in under 19s: recognition, referral and diagnosis³¹ and these guidelines were identified as the starting point for the adaptation process.

Figure 2: Total scores on AGREE ratings for Guidelines on screening/assessment of Autism in Children



Singapore 2nd edition¹⁵, Singapore¹⁶, France¹⁷, ESCAP = European Society of Child and Adolescent Psychiatry¹⁸, PSI = Psychological Society of Ireland¹⁹, CPS(A)= Canadian Paediatric Society (Assessment)²⁰, MF = Miriam Foundation²¹, CPS(ED)= Canadian Paediatric Society (Early Detection)²², Korea²³, AAN/CNS= American Academy of Neurology/ Child Neurology Society²⁴, USPSTF = United States Preventive Services Task Force²⁵, SIGN= Scottish Intercollegiate Guidelines Network²⁶, AACAP= American Academy of Child and Adolescent Psychiatry²⁷, Australia²⁸, New Zealand²⁹, AAP= American Academy of Pediatrics³⁰, NICE= National Institute for Health and Care Excellence³¹, Germany³², Finland³³.

Table 3: Scores on AGREE-II Subdomains of the Included Guidelines for Recognition, Referral and Diagnosis of Autism

Guideline	AGREE-II domain						Total
	Scope and Purpose	Stakeholder Involvement	Rigour of Development	Clarity	Applicability	Independence	
Finland	18	16	17	16	4	11	82
Germany	17	13	41	16	16	8	111
NICE	21	21	50	21	22	14	149
AAP	11	11	18	14	7	5	66
New Zealand	20	18	33	17	23	10	121
Australia	21	21	54	19	20	7	142
AACAP	17	14	36	19	6	11	103
SIGN	17	14	51	21	16	9	128
USPSTF	19	13	27	17	10	14	100
AAN/CNS	19	13	37	18	8	11	106
South Korea	6	3	11	7	6	8	41

CPS (ED)	8	6	13	8	7	4	46
MF	17	18	33	17	23	10	118
CPS (A)	14	12	9	15	8	11	69
PSI	18	17	22	17	7	2	83
ESCAP	15	9	27	8	13	12	84
France	19	16	34	12	4	11	96
Singapore	17	14	24	16	15	2	88
Singapore 2	18	20	50	20	21	11	140

Singapore 2nd edition¹⁵, Singapore¹⁶, France¹⁷, ESCAP = European Society of Child and Adolescent Psychiatry¹⁸, PSI = Psychological Society of Ireland¹⁹, CPS(A)= Canadian Paediatric Society (Assessment)²⁰, MF = Miriam Foundation²¹, CPS(ED)= Canadian Paediatric Society (Early Detection)²², Korea²³, AAN/CNS= American Academy of Neurology/ Child Neurology Society²⁴, USPSTF = United States Preventive Services Task Force²⁵, SIGN= Scottish Intercollegiate Guidelines Network²⁶, AACAP= American Academy of Child and Adolescent Psychiatry²⁷, Australia²⁸, New Zealand²⁹, AAP= American Academy of Pediatrics³⁰, NICE= National Institute for Health and Care Excellence³¹, Germany³², Finland³³.

Adaptation Process - Voting on Guidelines

Sixty-nine recommendations were reviewed and voted on by 11 members of the TF in Round 1 (see supplement 5). The TF endorsed 43 recommendations ($\geq 80\%$ level of agreement) and these were adopted. Twenty-six recommendations required revision. Before Round 2, eight recommendations were merged into four and two were excluded based on feedback from Round 1. In the second Round (see supplement 6), all 20 recommendations achieved $\geq 80\%$ endorsement. Therefore, 63 recommendations were adopted/adapted from NICE Guidelines for this CPG.

Guidelines for the Screening and Assessment of Autism in Children with Epilepsy

The nine recommendations regarding local pathway for recognition, referral and diagnostic assessment of possible ASD are in Box 1. (Adopted in Italics and Adapted in Underlined text)

Box 1 Local pathway for recognition, referral and diagnostic assessment of possible autism

1. Each region, where feasible, should have one body – the local autism strategy group - responsible for the planning and implementation of assessment of autism in children and young people with epilepsy.
2. The local autism strategy group should appoint a lead professional/clinician to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people with epilepsy. The aims of the group should include:
 - improving early recognition of autism in children with epilepsy by raising awareness of the features suggesting possible autism through multi-agency training (see features in appendix 1, 2 and 3 of Supplement 7)

- making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
- supporting the smooth transition to adult services for young people with epilepsy going through the diagnostic pathway
- ensuring data collection and audit of the pathway takes place

3. In each area where feasible, a multidisciplinary group (the autism team) should be set up. The core membership ideally should include or have regular access to the following if they are not in the team:

- Pediatric neurologist or pediatrician with expertise in epilepsy
- Speech and language therapist
- Occupational therapist
- Psychologist with training and experience in assessing and monitoring autistic children and young people.
- Child and adolescent psychiatrist
- Developmental pediatrician with expertise in autism

4. *Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. For example, a specialist health visitor or nurse, specialist teacher or social worker*

5. *The autism team should have the skills and competencies to:*

- *carry out an autism diagnostic assessment*

- *communicate with autistic children and young people and children and young people who may be autistic, and with their parents and carers, and sensitively share the diagnosis with them*

6. *Autism team members should:*

- *provide advice to professionals about whether to refer children and young people for autism diagnostic assessments*
- *decide on the assessment needs of those referred or when referral to another service will be needed*
- *carry out the autism diagnostic assessment*
- *share the outcome of the autism diagnostic assessment with parents and carers, and with children and young people if appropriate*
- *with parent or carer consent and, if appropriate, the consent of the child or young person, share information from the autism diagnostic assessment directly with relevant services, for example through a school visit by an autism team member*
- *offer information to children, young people and parents and carers about appropriate services and support*

7. Families of the child with epilepsy should have a clear point of contact within the autism team during the assessment process.

8. The autism team should either have the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with epilepsy but also other coexisting conditions including:

- a. severe visual and hearing impairments, motor disorders including cerebral palsy, severe learning (intellectual) disabilities, complex language disorders or complex mental health disorders
- b. looked-after children and young people (i.e. children not in the care of the parents who are being looked after by social services)

9. *If young people present at the time of transition to adult services, the autism team should consider carrying out the autism diagnostic assessment jointly with the adult autism team, regardless of the young person's intellectual ability.*

The 10 recommendations regarding recognition of children with epilepsy who may have autism are in Box 2.

Box 2 Recognizing children and young people with epilepsy who may have autism

10. Consider the possibility of autism if there are concerns about development or behaviour but be aware that there may be other explanations for individual signs and symptoms including overlap with epilepsy, other neurodevelopmental/neurogenetic conditions and psychosocial issues.

11. *Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others.*

12. When considering the possibility of autism and whether to refer a child or young person to the autism team, be critical about your professional competence and seek advice from a colleague if in doubt about the next step.

13. To help identify the features suggesting possible autism, use Appendices 1-3 Supplement 7. Do not rule out autism if the exact features described are not evident; they should be used for guidance, but do not include all possible manifestations of autism.

14. When considering the possibility of autism, be aware that:

- autism may be under-recognised in girls leading to underdiagnosis*
- signs and symptoms should be seen in the context of the child's or young person's overall development*
- signs and symptoms will not always have been recognised by parents, carers, children or young people themselves or by other professionals*
- when older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person's coping mechanisms and/or a supportive environment*
- it is necessary to account for cultural variation when considering language delays, particularly if the locally dominant language is not the family's first language or if early hearing difficulties are present*
- autism may be missed in children or young people with an intellectual disability*
- autism may be missed in children or young people who are verbally able*

- *important information about early development may not be readily available for some children and young people, for example looked-after children and those in the criminal justice system*
- *signs and symptoms may not be accounted for by disruptive home experiences or parental or carer mental or physical illness.*

15. When considering the possibility of autism, ask about the child or young person's use and understanding of their first language.

16. Do not rule out autism because of:

- *good eye contact, smiling and showing affection to family members*
- *reported pretend play or normal language milestones*
- *difficulties appearing to resolve after a needs-based intervention (such as a supportive structured learning environment)*
- *a previous assessment that concluded that there was no autism, if new information becomes available*

17. Discuss developmental or behavioural concerns about a child or young person with parents or carers, and the child or young person themselves if appropriate. Discuss sensitively the possible causes, which may include autism, emphasizing that there may be many explanations for the child's or young person's behaviour.

18. Be aware that if parents or carers or the child or young person themselves have not suspected a developmental or behavioural condition, raising the possibility may cause distress, and that:

- *it may take time for them to come to terms with the concern*
- *they may not share the concern.*

19. Take time to listen to parents or carers and, if appropriate, the child or young person, to discuss concerns and agree on any actions to follow including referral.

The eight guidelines regarding referring children and young people with epilepsy to the autism team are in Box 3.

Box 3 Referring children and young people with epilepsy to the autism team

20. Children with epilepsy who experience regression in language, motor or social skills should be referred for an autism assessment

21. Consider referring children and young people with epilepsy to the autism team if you are concerned about possible autism on the basis of reported or observed features suggesting possible autism (see appendix 1 to 3 in Supplement 7). Take account of:

- *the severity and duration of the features suggesting possible autism*
- *the extent to which the features suggesting possible autism are present across different settings (for example, home and school)*
- *the impact of the features suggesting possible autism on the child or young person and on their family*
- *the level of parental or carer concern and, if appropriate, the concerns of the child or young person*

- *factors associated with an increased prevalence of autism (see Appendix 4 Supplement 7)*
- *the likelihood of an alternative diagnosis.*

22. *If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:*

- *consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary*
- *referring to another service. That service can then refer to the autism team if necessary.*

23. *Be aware that tools to identify children and young people with an increased likelihood of autism may be useful in gathering information about features suggesting possible autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism. Also be aware that:*

- *a positive score on tools to identify an increased likelihood of autism may support a decision to refer but can also be for reasons other than autism*
- *a negative score does not rule out autism*

24. When referring children and young people with epilepsy to the autism team,
include in the referral letter the following information:

- Reported information from parents, carers and professionals about signs and/or symptoms of concern
- Your own observations of the signs and/or symptoms
- Information about the child's epilepsy including age of seizure onset, seizure types, treatment and previous and ongoing epilepsy related investigations

- Antenatal and perinatal history
- Developmental milestones
- Factors associated with an increased prevalence of autism (see Appendix 4 in Supplement 7)
- Relevant medical history and investigations
- Information from previous assessments

25. *Explain to parents or carers and, if appropriate, the child or young person, what will happen on referral to the autism team or another service.*

26. If you do not think concerns are sufficient to prompt a referral and you feel you are qualified to make this judgement, consider a period of watchful waiting. If you remain concerned about autism, reconsider your referral decision.

27. If the parents or carers or if appropriate, the child or young person with epilepsy, prefer not to be referred to the autism team, consider holding a meeting of all stakeholders (e.g. family, medical professionals) to discuss the rationale for referral, and advantages/disadvantages of onward referral for an autism assessment.

28. If a concern has been raised but there are no features suggesting possible autism or other reasons to suspect autism, convene a meeting of all stakeholders to discuss the next steps.

The **seven** guidelines regarding care after referral of children and young people with epilepsy to the autism team are in Box 4.

Box 4 After referral to the autism team

29. When a child or young person with epilepsy is referred to the autism team, at least one member of the autism team should consider whether to carry out:

- *an autism diagnostic assessment and/or*
- *an alternative assessment.*

30. Carry out an autism diagnostic assessment if there is regression in language or social skills in a child younger than 3 years.

31. When deciding whether to carry out an autism diagnostic assessment, take account of the following (unless the child is under 3 years and has regression in language or social skills – see recommendation 30):

- *the severity and duration of the signs and/or symptoms*
- *the extent to which the signs and/or symptoms are present across different settings (for example, home and school)*
- *the impact of the signs and/or symptoms on the child or young person and on their family or carer*
- *the level of parental or carer concern, and if appropriate the concerns of the child or young person*
- *factors associated with an increased prevalence of autism (see Appendix 4 supplement 7)*
- *the likelihood of an alternative diagnosis.*

32. If there is insufficient information to decide whether an autism diagnostic assessment is needed, gather any available information from healthcare

professionals. With consent from parents or carers and, if appropriate, the child or young person, seek information from schools or other agencies.

33. If there is uncertainty about whether an autism diagnostic assessment is needed after information has been gathered, offer a consultation to gather information directly from the child or young person and their family or carers.

34. Once it has been decided to carry out an autism diagnostic assessment, with consent from parents or carers (and the child or young person if appropriate):

- seek a report from the pre-school or school if one has not already been made available*
- gather any additional health or social care information, including results from hearing and vision assessments*

35. Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.

The guidance regarding the autism diagnostic assessment for children and young people with epilepsy are in Box 5.

Box 5 Autism diagnostic assessment for children and young people with epilepsy

36. Start the autism diagnostic assessment as early as possible and within 3 months of the referral to the autism team if possible.

37. A case coordinator/worker/clinician in the autism team should be identified for every child or young person with epilepsy who is to have an autism diagnostic assessment.

38. The autism case coordinator/worker/clinician should ideally:

- act as a single point of contact for the parents or carers and, if appropriate, the child or young person with epilepsy being assessed, through whom they can communicate with the rest of the autism team
- keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments
- arrange the provision of information and support for parents, carers, children and young people as directed by the autism team
- gather information relevant to the autism diagnostic assessment including details about the child's epilepsy and treatment

39. *Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand.*

40. *Include in every autism diagnostic assessment:*

- *detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns*
- *details of the child's or young person's experiences of home life, education and social care*
- *a developmental history, focusing on developmental and behavioural features consistent with ICD-11 or DSM-5 criteria (consider using an autism-specific tool to gather this information)*
- *assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-11 or DSM-5 criteria (consider using an autism-specific tool to gather this information)*
- *a medical history, including prenatal, perinatal and family history, and past and current health conditions*
- *a physical examination*
- *consideration of the differential diagnosis (see recommendation 41)*
- *systematic assessment for conditions that may coexist with autism (see recommendation 48)*
- *development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context*
- *communication of assessment findings to the parent or carer and, if appropriate, the child or young person*

41. Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations but also:

- Neurodevelopmental disorders:
 - specific language delay or disorder
 - a learning (intellectual) disability or global developmental delay
 - developmental coordination disorder
- Mental and behavioural disorders:
 - attention deficit hyperactivity disorder (ADHD)
 - mood disorder
 - anxiety disorder
 - attachment disorders
 - oppositional defiant disorder
 - conduct disorder
 - obsessive compulsive disorder
 - psychosis
- Other conditions:
 - severe hearing impairment
 - severe visual impairment
 - maltreatment (e.g. child exposed to harm/abuse)
 - selective mutism

42. *Consider which assessments are needed to construct a profile for each child or young person, for example:*

- *intellectual ability and learning style*
- *academic skills*

- *speech, language and communication*
- *fine and gross motor skills*
- *adaptive behaviour (including self-help skills)*
- *mental and emotional health (including self-esteem)*
- *physical health and nutrition*
- *sensory sensitivities*
- *behaviour likely to affect day-to-day functioning and social participation*
- *socialisation skills*

43. *If there are discrepancies during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider:*

- *gathering additional information from other sources and/or*
- *carrying out further autism-specific observations in different settings, such as the school, nursery, other social setting or at home*

44. *Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-11 or DSM-5 criteria.*

45. *Do not rely on any autism-specific diagnostic tool alone to diagnose autism.*

46. Be aware that in some children and young people with epilepsy there may be uncertainty about the diagnosis of autism, particularly in:

- children with epilepsy with very frequent seizures or who have a Developmental and Epileptic Encephalopathy

- children with epilepsy younger than 24 months
- children or young people with epilepsy with severe/profound ID or a developmental age of less than 18 months
- children or young people with epilepsy for whom there is a lack of available information about their early life (for example, some looked-after or adopted children)
- older teenagers with epilepsy
- children or young people with epilepsy who also have a complex coexisting mental health disorder (for example ADHD, conduct disorder, a possible attachment disorder), sensory impairment (for example severe hearing or visual impairment), or a motor disorder such as cerebral palsy

47. If the outcome of the autism diagnostic assessment clearly indicates that the child or young person does not have autism, consider referring them to appropriate services based on their profile.

48. Consider whether the child or young person with epilepsy may have any of the following as a coexisting condition, and if suspected carry out appropriate assessments and referrals:

- Mental and behaviour problems and disorders: ADHD, Anxiety disorders and phobias, Mood disorders, Oppositional defiant behaviour, Tics or Tourette syndrome, OCD, Self-injurious behaviour

- Neurodevelopmental problems and disorders: Global delay or a learning (intellectual) disability, Motor coordination problems or Developmental Coordination Disorder, Academic learning problems, for example in literacy or numeracy, Speech and language disorder
- Medical or genetic problems and disorders: Chromosome disorders Genetic abnormalities, including fragile X, Tuberous sclerosis, Muscular dystrophy, Neurofibromatosis
- Functional problems and disorders: Feeding problems, including restricted diets Urinary incontinence or enuresis, constipation, altered bowel habit, faecal incontinence or encopresis, Sleep disturbances, Vision or hearing impairment

49. Be aware that in children and young people with communication difficulties it may be difficult to recognise functional problems or mental health problems.

The four guidelines regarding provision after the autism assessment are in Box 6.

Box 6 After the autism diagnostic assessment

50. If there is uncertainty after the autism diagnostic assessment about the diagnosis, consider keeping the child or young person under review, taking into account any new information.

51. If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialized tertiary autism team if necessary):

- *continued uncertainty about the diagnosis*

- *disagreement about the diagnosis within the autism team*
- *disagreement with parents or carers or, if appropriate, the child or young person, about the diagnosis*
- *a lack of local access to particular skills and competencies needed to reach a diagnosis in a child or young person who has a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem*
- *a lack of response as expected to any therapeutic interventions provided to the child or young person*

52. During the autism diagnostic assessment, consider any potential risk of harm to, and from, the child or young person and take appropriate action.

53. Do not routinely perform any medical investigations as part of an autism diagnostic assessment, but consider the following in individual circumstances and based on physical examination, clinical judgment and the child or young person's profile:

- genetic tests, as recommended by your regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of an intellectual disability.

The nine guidelines regarding communicating the results of the autism assessment are in Box 7.

Box 7 Communicating the results from the autism diagnostic assessment

54. After the autism diagnostic assessment, discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person. Explain the basis of conclusions even if the diagnosis of autism was not reached.

55. Use recognized good practice when sharing a diagnosis with parents, carers, children and young people.

56. For children and young people with a diagnosis of autism, discuss and share information with parents or carers and, if appropriate, the child or young person, to explain:

- what autism is*
- how autism is likely to affect the child or young person's development and function*

57. Provide parents or carers and, if appropriate, the child or young person, with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn.

58. Share information, including the written report of the diagnostic assessment, with the child's primary health care professional/physician.

59. With parental or carer consent and, if appropriate, the consent of the child or young person, share information with key professionals involved in the child's or young person's care, including those in education and social care.

60. With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan.

61. For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion (for example about the conclusions of the assessment and the implications for the child or young person).

62. For children and young people with epilepsy who have a diagnosis of autism, it may be useful to discuss with parents or carers the risk of autism occurring in siblings and future children, but this discussion will also depend on the nature of the child's epilepsy and medical history.

The guidelines regarding information and support for families and carers is in Box 8.

Box 8 Information and support for families and carers

63. Provide individual information on support available locally for parents, carers, and autistic children and young people, according to the family's needs. This may include:

- *contact details for:*
 - *local and national support organisations (who may provide, for example, an opportunity to meet other families with experience of autism, or information about specific courses for parents and carers and/or young people)*
 - *organisations that can provide advice on welfare benefits*
 - *organisations that can provide information on educational support and social care information to help prepare for the future, for example transition to adult services*

Discussion

The Task Force on Paediatric Psychiatric Issues was able to adapt the NICE UK guidelines - ASD in under 19s: recognition, referral and diagnosis, for the pediatric epilepsy population. These adapted CPGs address key aspects of recognition, referral and diagnostic assessment in relation to autism in children and adolescents with epilepsy. These aspects have not been addressed previously in CPGs and provide important guidance for screening and assessment of autism in children with epilepsy.

The guidelines highlight the need for clear local pathways for recognition, referral and diagnostic assessment of possible autism in children and adolescents with epilepsy. In particular, there is a need for a lead professional to oversee the pathway and to ensure that children are referred to a multidisciplinary team with the necessary competencies to assess autism. The need for a team approach reflects the fact that autism is a complex neurodevelopmental disorder demanding a multidisciplinary team with a patient-centered approach to improve outcomes³⁴. Regarding key issues to consider in the recognition of children and young people with epilepsy who may have autism, the guidelines highlight the need to suspect autism if there are developmental or behavioral concerns but also to consider other possible explanations including other neurodevelopmental, mental and behavioral disorders. Additionally, there is a need to consider that autism may be under-recognized in girls, verbally able children and older children. Additionally, the guidelines indicate that any child with epilepsy who experiences a loss of skills (language, social, or motor) should be referred for an autism assessment. In such situations, clinicians should consider whether the observed regression is due to an epileptic encephalopathy event, such as Epileptic Encephalopathy with Spike-Wave Activation in Sleep (EE-SWAS). It is also important to determine whether the autism-like symptoms are temporary or represent a more persistent neurodevelopmental pattern. Screening tools may be helpful in organizing and structuring the information gathered during assessment, but they cannot be used to confirm or rule out an autism diagnosis^{35,36}.

The guidelines for practice after referral to the autism team include the need to collect comprehensive information about the child's symptoms and the need to collect information from a range of settings. Guidelines around the diagnostic assessment include the need to begin the assessment within three months of referral, the core assessment elements including the need to consider differential diagnosis and coexisting conditions and the use of multiple sources of information to characterise the child's symptoms. An autism diagnosis should be made with respect to ICD-11³⁷ or DSM-5³⁸ criteria with careful consideration required when assessing children with epilepsy under 24 months of age or with developmental levels below 18 months. It is important to note that children and young people with epilepsy under 24 months of age or who have a developmental level under 18 months of age can be diagnosed with autism³⁹, but caution is needed when interpreting their symptoms due to developmental variability and evolving phenotypes.

The guidelines for communicating the results of the diagnostic assessment emphasize the importance of providing timely and sensitive feedback and the central role of coordinated family-centered care pathways. They highlight the need to share information with relevant medical, educational, and social care professionals, as well as to offer follow-up discussions to explain the conclusions and implications of the diagnosis. Regarding information and support for families of children and adolescents with epilepsy, the guidelines stress the need to provide tailored, individual guidance based on each family's needs. Families should be offered connection with relevant support organizations and be given resources to support future planning, such as preparing for the transition to adult services where relevant.

Implications and Future Research Directions

All children and young people with epilepsy should be referred for an autism assessment if there are concerns about development and behavior suggesting possible autism. In children with epilepsy who experience regression in language, motor, or social skills, autism should be considered and a formal assessment initiated, alongside a thorough neurological evaluation. The autism team for children and young people with epilepsy should either have the skills (or have access to professionals that have the skills) needed to carry out an autism

diagnostic assessment, for children and adolescents with epilepsy, though the exact make-up of this team may look different in different contexts. Autism specific screening instruments are useful but should not be the sole source of information regarding decisions on further referrals.

Future research should focus on validating existing autism screening tools in the pediatric epilepsy population including in subgroups e.g., children with Developmental and Epileptic Encephalopathies (DEEs) and children with intellectual disability and epilepsy. There may or may not be a need to develop epilepsy-specific instruments that could account for seizure- or treatment related cognitive fluctuations and co-occurring conditions. Additional work should explore the influence of intellectual disability, medication, and other comorbidities on autism screening outcomes, as well as the feasibility and effectiveness of implementing systematic screening in pediatric epilepsy clinics as well as referral pathways for interventions.

Limitations

There are a number of limitations that need to be considered when interpreting the results of our systematic search and adaptation of guidelines. The date for our systematic search for guidelines for screening for autism in children was November 2025 and we did not consider guidelines published after this date. Participation in the ADAPTE process was by invitation and respondents may not be representative of all professionals who work with children with epilepsy.

Conclusion

There is currently little evidence or guidance on how to assess children and young people with epilepsy for autism. The ADAPTE process allowed us to adopt already published guidelines not specific to epilepsy, and as appropriate to adapt these for children and young people with epilepsy. These CPGs can help improve outcomes in autism assessment for children with epilepsy by enhancing early identification, reducing variability in practice, and supporting clinical decision-making.

Funding

There was no specific funding for this project.

Acknowledgements

The authors thank University Librarian Viviane Castanho for his assistance in the systematic search process.

Disclosures

RS has received institutional and research support from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Angelini, UnEEG, Neuronostics and Jazz/GW pharma outside the submitted work. He holds institutional grants from funding bodies all outside this work. JS has received institutional and research support from Jazz/GW Pharma, outside of this work. LG has received funds as Associate Editor of “Seizure: European Journal of Epilepsy. SA has Received payment as Patient and Public Involvement Lead for 2 large studies and as a lay member of a Research Ethics Committee. He has also received Received per diem payment as a speaker at the IEC Lisbon 2025. NS has served on scientific advisory boards for Jazz Pharma, BioMarin, Arvelle, Marinus and Takeda, UCB, Stoke Therapeutics; has received speaker honoraria from Jazz, UCB, Angelini, Biomarin, Livanova; has served as an investigator for Marinus, Biomarin, UCB, Jazz, Roche. KV is Associate Editor of *Epilepsy & Behavior* and *Epilepsia*. She is currently collaborating on research with Ulysses Neuroscience, supported by the LouLou Foundation. She has served as a consultant or received honoraria for lectures from Lundbeck-Longboard, Biocodex, UCB Pharma, Takeda, Praxis, Abbott, PTC, United Medical, and Latin-American Pharmaceutical Industry (ACHE, Prati-Donaduzzi, Eurofarma, EMS, and Zodiac Pharmaceuticals). She has been the PI for clinical trials for Lundbeck-Longboard, Takeda, Praxis, and the Latin-American Pharma Industry (Prati-Donaduzzi Pharmaceuticals). These activities are

unrelated to this work. JS has been a past consultant for Stoke Pharmaceuticals, has received research funding from Jazz Pharmaceuticals and Royalties from Springer. CR, FB, ED, MLS, ED, KAD have no COIs to disclose.

ORCID ID

[CR: https://orcid.org/0000-0002-5135-383X](https://orcid.org/0000-0002-5135-383X)

[JS: https://orcid.org/0000-0002-6023-9430](https://orcid.org/0000-0002-6023-9430)

[FB: https://orcid.org/0000-0003-0928-1577](https://orcid.org/0000-0003-0928-1577)

[EH: https://orcid.org/0000-0002-6484-5972](https://orcid.org/0000-0002-6484-5972)

[CT: https://orcid.org/0000-0002-8567-9547](https://orcid.org/0000-0002-8567-9547)

[NS: https://orcid.org/0000-0002-8120-0287](https://orcid.org/0000-0002-8120-0287)

[LG: https://orcid.org/0000-0001-6398-8632](https://orcid.org/0000-0001-6398-8632)

[RS: https://orcid.org/0000-0002-1183-6933](https://orcid.org/0000-0002-1183-6933)

[KD: https://orcid.org/0000-0002-0276-9660](https://orcid.org/0000-0002-0276-9660)

[MLS: https://orcid.org/0000-0002-1937-1026](https://orcid.org/0000-0002-1937-1026)

[ED: https://orcid.org/0000-0002-6645-932X](https://orcid.org/0000-0002-6645-932X)

[CCT: https://orcid.org/0000-0003-2918-3819](https://orcid.org/0000-0003-2918-3819)

[SA: https://orcid.org/0000-0003-3874-9749](https://orcid.org/0000-0003-3874-9749)

[KV: https://orcid.org/0000-0002-5008-0809](https://orcid.org/0000-0002-5008-0809)

References

- ¹Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2014). Neurobehavioral comorbidities in children with active epilepsy: a population-based study. *Pediatrics*, *133*(6), e1586-e1593.
- ²Surén, P., Bakken, I. J., Aase, H., Chin, R., Gunnes, N., Lie, K. K., ... & Stoltenberg, C. (2012). Autism spectrum disorder, ADHD, epilepsy, and cerebral palsy in Norwegian children. *Pediatrics*, *130*(1), e152-e158.
- ³ Lukmanji, S., Manji, S. A., Kadhim, S., Sauro, K. M., Wirrell, E. C., Kwon, C. S., & Jette, N. (2019). The co-occurrence of epilepsy and autism: A systematic review. *Epilepsy & Behavior*, *98*, 238-248.
- ⁴Tye, C., Runicles, A. K., Whitehouse, A. J., & Alvares, G. A. (2019). Characterizing the interplay between autism spectrum disorder and comorbid medical conditions: An integrative review. *Frontiers in psychiatry*, *9*, 751.
- ⁵Subramaniam, V. R., Goldstein, J., Mu, L., & Kwon, C. S. (2024). In-hospital outcomes in people with autism and epilepsy—A population-based study. *Epilepsy Research*, *205*, 107417.

⁶Institute of Medicine (US) Committee on Standards for Developing Trustworthy Clinical Practice Guidelines. (2011). *Clinical practice guidelines we can trust*. National Academies Press.

⁷Jetté, N., Kirkpatrick, M., Lin, K., et al. (2022). What is a clinical practice guideline? A roadmap to their development. Special report from the Guidelines Task Force of the International League Against Epilepsy. *Epilepsia*, 63, 1920–1929. <https://doi.org/10.1111/epi.17312>

⁸Klugar, M., Lotfi, T., Darzi, A. J., et al. (2024). GRADE guidance 39: Using GRADE-ADOLPMENT to adopt, adapt, or create contextualized recommendations from source guidelines and evidence syntheses. *Journal of Clinical Epidemiology*, 174, 111494. <https://doi.org/10.1016/j.jclinepi.2024.111494>

⁹Schünemann, H. J., Wiercioch, W., Brozek, J., et al. (2017). GRADE Evidence to Decision (EtD) frameworks for adoption, adaptation, and de novo development of trustworthy recommendations: GRADE-ADOLPMENT. *Journal of Clinical Epidemiology*, 81, 101–110. <https://doi.org/10.1016/j.jclinepi.2016.09.009>

¹⁰Mendez MA, Canitano R, Oakley B, San José-Cáceres A, Tinelli M, Knapp M, Cusack J, Parellada M, Violland P, Derk Plas JR, Murphy DGM, Quoidbach V, Arango C. Autism with co-occurring epilepsy care pathway in Europe. *European Psychiatry*. 2023;66(1):e61. doi:10.1192/j.eurpsy.2023.2426

¹¹Fervers B, Burgers JS, Voellinger R, Brouwers M, Browman GP, Graham ID, et al. Guideline adaptation: an approach to enhance efficiency in guideline development and improve utilisation. *BMJ Qual Saf*. 2011 Mar;20(3):228–36. doi:10.1136/bmjqs.2010.043257.

¹²Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. *PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation*. *Ann Intern Med*. 2018;169(7):467–473. doi:10.7326/M18-0850

¹³Brouwers MC, Kho ME, Browman GP, Burgers JS, Cluzeau F, Feder G, et al. AGREE II: advancing guideline development, reporting and evaluation in health care. *CMAJ*. 2010 Dec 14;182(18):E839–42. doi:10.1503/cmaj.090449.

¹⁴ Dalkey, N., & Helmer, O. (1963). An experimental application of the Delphi method to the use of experts. *Management science*, 9(3), 458-467.

¹⁵College of Paediatrics and Child Health, Singapore. *Clinical Practice Guidelines on Autism Spectrum Disorder in Children and Adolescents*. Singapore: College of Paediatrics and Child Health; 2023.

¹⁶Academy of Medicine Singapore–Ministry of Health Clinical Practice Guidelines Workgroup on Autism Spectrum Disorders. Academy of Medicine Singapore–Ministry of Health clinical practice guidelines: Autism spectrum disorders in pre-school children. *Singapore Med J*. 2010;51:255–63.

¹⁷Haute Autorité de Santé. *Autism spectrum disorder: Warning signs, detection, diagnosis and assessment in children and adolescents. Clinical practice guidelines method*. Paris: Haute Autorité de Santé; 2018.

¹⁸Fuentes J, Hervás A, Howlin P; ESCAP ASD Working Party. ESCAP practice guidance for autism: a summary of evidence-based recommendations for diagnosis and treatment. *Eur Child Adolesc Psychiatry*. 2021;30(6):961–84.

¹⁹Psychological Society of Ireland, Special Interest Group in Autism. *Professional Practice Guidelines for the Assessment, Formulation, and Diagnosis of Autism in Children and Adolescents*. 2nd ed. Dublin: PSI; 2022.

²⁰Brian JA, Zwaigenbaum L, Ip A; Canadian Paediatric Society ASD Guidelines Task Force. Standards of diagnostic assessment for autism spectrum disorder. *Paediatr Child Health*. 2019;24(7):444–51.

²¹Canadian Paediatric Society; The Miriam Foundation. *Screening, Assessment, and Diagnosis of Autism Spectrum Disorders in Young Children: Canadian Best Practice Guidelines*. Montreal (QC): The Miriam Foundation; 2008.

²²Zwaigenbaum L, Brian JA, Ip A; Canadian Paediatric Society ASD Guidelines Task Force. Early detection for autism spectrum disorder in young children. *Paediatr Child Health*. 2019;24(7):424–32

²³Kim JI, Yoo HJ. Diagnosis and Assessment of Autism Spectrum Disorder in South Korea. *J Korean Acad Child Adolesc Psychiatry*. 2024;35(1):15–21.

²⁴Filipek PA, Accardo PJ, Ashwal S, Baranek GT, Cook EH Jr, Dawson G, Gordon B, Gravel JS, Johnson CP, Kallen RJ, Levy SE, Minshew NJ, Ozonoff S, Prizant BM, Rapin I, Rogers SJ, Stone WL, Teplin SW, Tuchman RF, Volkmar FR; Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. Practice parameter: screening and diagnosis of autism. *Neurology*. 2000;55(4):468–79.

²⁵Siu AL, Bibbins-Domingo K, Grossman DC, Baumann LC, Davidson KW, Ebell M, et al.; US Preventive Services Task Force. Screening for autism spectrum disorder in young children: US Preventive Services Task Force recommendation statement. *JAMA*. 2016;315(7):691–6.

²⁶Scottish Intercollegiate Guidelines Network. *Assessment, diagnosis and interventions for autism spectrum disorders*. Edinburgh: SIGN; 2016. (SIGN publication no. 145)

²⁷Volkmar F, Siegel M, Woodbury-Smith M, King B, McCracken J, State M; American Academy of Child and Adolescent Psychiatry Committee on Quality Issues. Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *J Am Acad Child Adolesc Psychiatry*

²⁸ Whitehouse AJO, Evans K, Eapen V, Wray J; Autism CRC. *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia*. 2nd ed. Brisbane: Autism CRC; 2023.

²⁹Whaikaha – Ministry of Disabled People; Ministry of Education. *Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau*. 3rd ed. Wellington: Whaikaha; 2022.

³⁰Hyman SL, Levy SE, Myers SM; Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*. 2020;145(1):e20193447.

³¹National Institute for Health and Care Excellence (NICE). *Autism spectrum disorder in under 19s: recognition, referral and diagnosis [Internet]*. Clinical Guidance CG128. London: NICE; published 28 September 2011, last updated 20 December 2017. Available from: <https://www.nice.org.uk/guidance/CG128>.

³²Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie (DGKJP); Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde (DGPPN), et al. *Autismus-Spektrum-Störungen im Kindes-, Jugend- und Erwachsenenalter. Teil 1: Diagnostik*.

Interdisziplinäre S3-Leitlinie. AWMF Register No. 028-018. Langversion, Konsensuskonferenz 24./25.04.2015; Stand Text Leitlinie: 23.02.2016. Frankfurt am Main: DGKJP / DGPPN; 2016

³³Suomalaisen Lääkäriseuran Duodecimin, Suomen Lastenpsykiatriyhdistyksen, Suomen Nuorisopsykiatrisen Yhdistyksen, Suomen Kehitysvammalääkäreiden, Suomen Lastenneurologisen Yhdistyksen & Suomen Psykiatriyhdistyksen työryhmä. *Autismikirjon häiriö: Käypä hoito –suositus.* Helsinki: Duodecim; 2024.

³⁴Uen CG, Campbell K, Stoddard G, Carbone PS. Patient-Centered Outcomes in an Interdisciplinary Clinic for Complex Children with Autism. *J Dev Behav Pediatr.* 2021 Apr 1;42(3):182-190. doi: 10.1097/DBP.0000000000000877. PMID: 33086336; PMCID: PMC7990680.

³⁵Lord C, Elsabbagh M, Baird G, Veenstra-Vanderweele J. Autism spectrum disorder. *Lancet.* 2018 Aug 11;392(10146):508-520. Doi: 10.1016/S0140-6736(18)31129-2. Epub 2018 Aug 2. PMID: 30078460; PMCID: PMC7398158.

³⁶Hyman SL, Levy SE, Myers SM; Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics.* 2020;145(1):e20193447.

³⁷American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

³⁸World Health Organization. (2019). International classification of diseases for mortality and morbidity statistics (11th Revision). <https://icd.who.int/>

³⁹ Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, et al. The Lancet Commission on the future of care and clinical research in autism. *Lancet*. 2022;399:271–334. Doi: 10.1016/s0140-6736(21)01541-5.