



HAUTE AUTORITÉ DE SANTÉ

BEST PRACTICE GUIDELINE

Autism spectrum disorder

Warning signs, detection, diagnosis and assessment in children
and adolescents

Clinical practice guidelines method

GUIDELINES

February 2018

The best practice guidelines (BPG) are defined in the health field as methodically developed proposals to assist the practitioner and the patient to find the most appropriate care in given clinical circumstances.

The BPGs are rigorous summaries of the state of the art and scientific data at a given time, described in the evidence report [in French]. They do not exempt the health professional from exercising discretion in the patient's treatment; this must be the treatment considered to be most appropriate depending on their own findings and the patient's preferences.

This best practice guideline has been developed according to the method summarised in the evidence report and in the HAS methodology guide available online:

“Development of best practice guidelines – Clinical practice guidelines method”.

The objectives of this guideline, the population and the professionals involved in its implementation are summarised on the last page (information sheet) and described in detail in the evidence report.

This sheet and the guideline summary can be downloaded from www.has-sante.fr.

Grades of guidelines

A	Established scientific evidence Based on studies with a high level of evidence (level of evidence 1): randomised controlled trial with high power and without major bias or meta-analysis of randomised controlled trials, decision analysis based on well conducted studies.
B	Scientific presumption Based on scientific presumption provided by studies with an intermediate level of evidence (level of evidence 2) such as low power randomised controlled trials, well conducted non-randomised controlled studies, cohort studies.
C	Low level of evidence Based on studies with low level of evidence such as case-control studies (level of evidence 3), retrospective studies, case-series studies, comparative studies with major biases (level of evidence 4).
EC	Expert consensus In the absence of studies, the guidelines are based on agreement between experts in the working group after consultation with the reading group. The absence of grading does not mean that the guidelines are not relevant and useful. However, it should prompt additional studies.

The evidence report of this assessment [in French] can be downloaded from www.has-sante.fr

Haute Autorité de Santé

Communications and Information Department
5, avenue du Stade de France – F 93218 Saint-Denis La Plaine Cedex
Tel.: +33 (0)1 55 93 70 00 – Fax: +33 (0)1 55 93 74 00

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Abbreviations and acronyms

ALD..... *affection de longue durée* [chronic condition]

ARS *agence régionale de santé* [regional health agency]

CRA *centre de ressources autisme* [autism resource centre]

DSM-5... Diagnostic and Statistical Manual of Mental Disorders – 5th edition

MDPH ... *maison départementale pour les personnes handicapées* [regional home for the disabled]

PMI..... (public service of) *protection maternelle et infantile* [maternal and child protection]

NDD neurodevelopmental disorders

ASD autism spectrum disorder

Introduction

The best practice guideline on the topic “Autism spectrum disorder: diagnosis and assessment in children and adolescents” was developed at the request of the Minister of Social Affairs, Health and Women's Rights, as well as the Secretary of State for the Disabled and the Fight against Exclusion, which jointly asked HAS to update the “Professional practice guidelines for the diagnosis of autism” which were developed in 2005 by the French Federation of Psychiatry (FFP) in partnership with HAS¹.

The request for update is justified by the advancement of knowledge and pathways over the course of 10 years in the fields of detection, diagnosis and early interventions for children and adolescents with autism spectrum disorder (ASD), and by the French publication in 2015 of the updated *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5).

This guideline is for all professionals involved in the detection and diagnosis of ASD in children and adolescents. These professionals are numerous and are involved in part or all of the pathway from detection to diagnosis depending on their mode and place of practice. This document distinguishes:

- first-line professionals:
 - early childhood professionals (childcare assistants, childminders, early childhood educators, specialised educators, etc.),
 - national education professionals (national education teachers, nurses, psychologists and physicians),
 - healthcare professionals working in private practice, in maternal and child protection (PMI) or multidisciplinary health centres, namely general practitioners, paediatricians, allied health professionals (nurses, paediatric nurses, speech therapists, psychomotor therapists, physiotherapists, occupational therapists, orthoptists) and psychologists;
- second-line professionals
 - coordinated professionals in a multidisciplinary team comprised of professionals specifically trained in neurodevelopmental disorders and autism spectrum disorder: paediatric psychiatry teams (children's psychiatry departments including medico-psychological centres - CMP), paediatrics departments, centre for early medico-social action (CAMSP), medico-psycho-pedagogical centre (CMPP), networks of specialised care in the diagnosis and assessment of autism or private practitioners coordinated by a doctor,
 - ear-nose-throat (ENT) and ophthalmology (OPH) specialists;
- third-line professionals:
 - professionals practising at autism resource centres or at hospital centres for additional specialised opinions, namely in paediatric neurology, clinical genetics and medical imaging.

¹ FFP, HAS, Baghdadli A. Recommandations pour la pratique professionnelle du diagnostic de l'autisme. Paris; Saint-Denis La Plaine; 2005.

Issues and objectives of the guideline

In very young children with signs of unusual development, the central issue in detection and then early diagnosis is the opportunity to implement interventions suitable for ASD that are global, personalised and coordinated. If possible, this should be accomplished before 4 years of age², to encourage their development and learning in the areas affected by the ASD and reducing associated disabilities. It is also about contributing to the child's ability to blossom and thrive, in addition to the well-being of the child and his/her family.

The objectives for improvement of professional practices in the diagnosis of ASD are to:

- continue the observed reduction of the mean age of diagnosis;
- improve the diagnostic pathway, in particular to reduce the time to diagnosis;
- articulate the diagnosis and personalised plan of early interventions in the shortest time possible.

The objective of this work is to optimise the detection of children and adolescents with signs of ASD or unusual development or at risk of developing an ASD and to harmonise practices and procedures for an initial diagnosis of ASD in children or adolescents under 18 years of age.

This document is based on the following principles:

- it aims primarily to improve the practices for detecting and diagnosing ASD, and supplements the 2005 guidelines on diagnosis and the 2012 guidelines on therapeutic, educational and pedagogical interventions, to promote with their families a coherent and fluid pathway for the children and adolescents affected;
- the recommendations in this document are not intended to define a single model of the diagnostic pathway, which can be generalised to all patients; rather, they provide tools to implement it in a more fluid way;
- the significant differences, depending on the territory, in available care, medical demographics, and available skills in neurodevelopment means that the ARS, in close connection with the parties involved in the territory, can choose the organisations and evolution of care strategies that are most relevant in terms of the identified needs of the territory.

Definitions and general information

The characteristics of autism vary greatly from one person to the next and cover a broad spectrum. The classification and diagnosis of autism are also constantly changing and have been the subject of many discussions. The Diagnostic and Statistical Manual of Mental Disorders, commonly called DSM (available in French since 2015 in its fifth edition: DSM-5) and the International Classification of Diseases are the two most common medical classifications. Since 2005, the recommended medical classification in France has been ICD-10, pending ICD-11. The most up-to-date classification today is the DSM-5, in which the term "autism spectrum disorder (ASD)" now replaces the term "pervasive developmental disorders (PDD)". In the DSM-IV, PDD included several categories (autistic disorder, Asperger syndrome, pervasive developmental disorder not otherwise specified ([PDD-NOS], childhood disintegrative disorder, and Rett syndrome). In the DSM-5, there is now only a single diagnostic category characterised by two dimensions of symptoms: A. "Persistent deficits in social communication and social interaction across multiple contexts" and B. "Restricted, repetitive patterns of behaviour, interests, or activities" (Appendix 1).

² For coordinated education and treatment interventions in children and adolescents, refer to the following guideline: HAS, Anesm. Autism and other PDDs: coordinated education and treatment interventions in children and adolescents. Saint-Denis La Plaine; 2012. http://www.has-sante.fr/portail/jcms/c_953959/fr/autisme-et-autres-troubles-envahissants-du-developpement-interventions-educatives-et-therapeutiques-coordonnees-chez-lenfant-et-ladolescent

ASD is positioned in the DSM-5 among neurodevelopmental disorders, as are intellectual developmental, communication, attention-deficit/hyperactivity, specific learning, and motor disorders. The DSM-5 criteria make it possible to specify the severity of the ASD through three levels of support required for the individual to function, as well as to specify whether the following conditions co-occur: *“intellectual impairment, language impairment, known medical or genetic condition or environmental factor, another developmental, mental, or behavioural disorder, or catatonia”*. The DSM-5 criteria do not take the place of an evaluation of the child’s functioning.

The DSM-5 also introduces a new diagnosis of “social communication disorder”. This diagnosis applies to individuals who have problems with verbal and nonverbal social communications, leading to limitations in social participation and academic success or work performance, but who do not have the stereotypies or repetitive behaviours and restricted interests that are characteristic of autism spectrum disorder.

Neurodevelopment refers to the set of mechanisms that guide the way the brain develops, orchestrating the brain functions (motor function, language, cognitive, sensory integration, psychic structuring, behaviour, etc.). It is a dynamic process, influenced by biological, genetic, sociocultural, affective and environmental factors. It starts very early, in the prenatal period, and continues until adulthood. Each day, this maturation modifies the child's abilities. The rate of neurodevelopment varies depending on the individual, but it follows key steps that connect fluidly in the course of a regular development. Disturbance of these developmental processes of the brain leads to a neurodevelopmental disorder (NDD), corresponding to difficulties of varying significance in one or more of these brain functions. ASD has aspects in common with other NDDs as regards clinical signs and risk factors, so the multiprofessional diagnostic process will be focused on examining development and identification of co-occurring disorders. However, the justified inclusion of ASD among neurodevelopmental disorders must not lead to neglect of its specific semiology or of the need for therapeutic and rehabilitative actions suitable for ASD.

In the remainder of this document, “child” will refer to both children and adolescents. Guidelines more specifically directed toward adolescents will mention the term “adolescent” in their wording.

Guidelines

1. From warning signs to the dedicated consultation in primary care

The first step of the pathway of the child and his/her family starts with the identification of warning signs and continues to the dedicated consultation in primary care (see diagram 1, end of chapter).

1.1 Identification of warning signs

Any party involved can check for warning signs: parents, healthcare or non-healthcare professionals (early childhood professionals, teachers, psychologists, etc.). This action involves identifying, observing and detecting one (or more) unusual sign(s) likely to indicate a developmental abnormality.

A check for ASD warning signs is recommended as part of the medical exam carried out during each mandatory health check-up in children 0 to 6 years of age³ by the doctor who provides the child's regular care⁴, or by the PMI physician or the school doctor as part of routine visits carried out at school.

► Warning signs

Box 1. Major warning signs of ASD

Regardless of age

- Parental concern about their child's development, especially in terms of social communication and language
- Regression of language or interpersonal skills, in the absence of abnormalities in the neurological examination

In young children

- Lack of babbling, pointing or other social communication gestures at age 12 months and older (say hello, goodbye, etc.)
- No words at age 18 months and older
- No word combinations (non-echolalic) at age 24 months and older

³ In France, children have 20 mandatory medical examinations between 0 and 6 years of age, including 3 that result in a medical certificate which is sent to the health authorities. The objectives of these exams include "monitoring of weight-for-height growth (age-specific weight and height) and physical development, psychomotor monitoring, emotional monitoring of the child, early detection of abnormalities or disorders, and vaccinations" (see the website [service-public.fr: https://www.service-public.fr/particuliers/vosdroits/F967](https://www.service-public.fr/particuliers/vosdroits/F967)). Moreover, mandatory medical visits and screening are provided in schools (when the child is 6 years old) and the medical exam prior to the assignment of the minor student to regulated work (technical schools). National education nurses perform a nurse screening when the child is 12 years old. (see http://www.education.gouv.fr/pid285/bulletin_officiel.html?cid_bo=91594).

⁴ This doctor is usually the doctor who provides the child's regular care (general practitioner or paediatrician) or the doctor from maternal and child welfare (PMI).

Parental concern

Any parental concern about development, and especially about language and social interactions, should be considered a major warning sign (see Box 1).

This should lead to a comprehensive assessment of the child's development by the doctor who provides the child's regular care, as part of a dedicated consultation for detection of an ASD (see section 1.2).

Other warning signs

Before 18 months

In a child under 18 months of age, there are currently no pathognomonic markers for progression towards an ASD.

However, in this age range, some troubles (or abnormalities) other than those related to the child's communication may be useful as early indicators of a neurodevelopmental disorder (NDD). These may be abnormalities in the following areas:

- level of concentration ("child who is too calm or irritable");
- sleep (excessive time to fall asleep or awakenings);
- dietary diversification (refusing to try new foods or textures, food rituals);
- regulation of emotions (unexplained bouts of crying) and tonic-postural reaction ("does not like" being held);
- development of his/her motor skills;
- unusual exploration of human and physical "objects" in the environment, regardless of the sensory modality used (for example, lining up objects or turning the lights on/off).

The persistence of such indicators, as well as major warning signs (see Box 1), requires a comprehensive assessment of all areas of the child's development, including social communication.

Around 18 months

The warning signs of ASD are more easily identifiable around 18 months of age, although they may be present earlier, from about 12 months (see Box 1).

Specifically, these may be problems in the following areas:

- interpersonal involvement (with parents and peers);
- social attention and reciprocity (initiation, response and maintaining joint attention, directed gaze, shared smile, pointing coordinated with gaze);
- social reaction (response to first name);
- receptive language (understanding simple instructions) and expressive language (repeated syllables, then regular and appropriate use of several words);
- socio-imitative and symbolic play;
- sensory responses (seeking or avoiding sensations).

None of these signs on its own has a predictive value, but the combination of two or more signs requires a comprehensive clinical assessment of the child's development.

Beyond 18 months and until adolescence

In children over 18 months of age, the above-mentioned signs or the presence of early and persistent interpersonal difficulties, in combination with behavioural abnormalities and abnormally repetitive, restricted interests and stereotypies, should alert to the possibility of an ASD. Examples of interpersonal difficulties include: trouble making friends; trouble engaging, following or participating in a conversation; trouble taking social initiatives (outings, invitations, etc.); trouble understanding or interpreting intentions; trouble with language expressions and idioms; etc.

There may be potentially suggestive signs: inappropriate use of language; decreased contact or indifference or, in some cases, excessive familiarity; trouble recognising the emotions of others; swaying and other stereotypies; resistance to change which may lead to rituals; behavioural disorders (aggression, oppositional behaviour); etc.

ASD warning signs may be detected later in childhood or even in adolescence. This is especially true when there is no coexisting intelligence development disorder or when the autistic symptoms are low in severity. These signs are sometimes more obvious when the demands of the social or school environment are greater (for example, during school transitions, such as starting secondary school around age 11) and these demands exceed the child's adaptive capacities.

Regardless of the child's age

A regression of language or interpersonal skills should also lead to screening for ASD, regardless of the child's age, when there are no abnormalities in the neurological examination that would immediately point toward another diagnosis (for example, a neurodegenerative condition).

► **Ways to look for warning signs of neurodevelopmental disorders (first-line professionals)**

In case of parental concern about their child's development, or in case of warning signs detected by any professional⁵, parents should be referred to the doctor who provides the child's regular care, the childcare centre doctor, or national education doctor for a medical consultation for screening. At this initial consultation, a dedicated consultation in primary care (general practitioner, paediatrician or PMI doctor) is scheduled within 3 weeks. A comprehensive clinical assessment of the child's development will be carried out during the dedicated consultation (see section 1.2).

All early childhood and childhood professionals should pay close attention to the development of social communication in all children. This approach needs to be early and continuous throughout the child's development, with increased monitoring when the child enters the preschool and school.

During each mandatory health check-up for infants and children and during planned medical visits at schools (entry into school at 3 years of age, visit at 5 years of age), assessment of communication, motor skills (gross and fine) and language should be part of the clinical assessment.

► **Examples of tools available**

The check for warning signs of unusual development is based on items in the health booklet. It can be completed through a parental questionnaire on the child's development, such as: the French Communicative Development Inventories (IFDC); the Brunet-Lézine Scale (revised); the Denver Scale; the simplified Gesell test (Appendix 2).

The results of this test should be mentioned in the health booklet.

► **Monitoring point**

Warning signs may be identified later and less often in some girls than boys, due to a clinical presentation that only partly coincides with the clinical presentation in boys (for example, girls exhibit less change in social behaviour, fewer repetitive behaviours).

1.2 Detection of signs of ASD during a dedicated consultation

Children involved

A routine screening for ASD in the general population (universal screening) is not recommended in the absence of sufficiently sensitive and specific tools.

Conversely, screening for signs of ASD is recommended in children with warning signs (see section 1.1) or who have a significantly higher risk of ASD or NDD than the general population (see Box 2).

Siblings of children with ASD have a higher risk of ASD or other NDDs than the general population, so routine screening in this group is recommended. This screening should follow a specific protocol to detect signs suggestive of ASD starting at age 1 year and continuing throughout the children's developmental monitoring.

⁵ These are professionals in contact with the child in the early childhood or childhood sectors (childcare workers and early childhood educators working at childcare centres, childminders, child protection services, etc.), teachers (of children from 3 to 18 years of age), etc.

Box 2. Children who need special attention (because of risk of ASD and other NDDs) and for whom screening for signs of ASD is recommended

- Children with ASD warning signs, including any parental concern about the child's development, especially in terms of social communication and language (see 1.1)
- Children born prematurely or exposed to risk factors during pregnancy (medications such as antiepileptics, psychotropics; substances such as alcohol, etc.)
- Children with neurodevelopmental disorders in the context of known genetic or chromosomal abnormalities usually associated with ASD
- Siblings of children with ASD, starting at 1 year of age

Process and examples of tools

In all cases, the recommended screening process includes a comprehensive clinical assessment of the child's development during a dedicated consultation.

For children 16 to 30 months of age, it can be based on the M-CHAT⁶. If the results confirm a risk of ASD, it can be supplemented with a more precise, structured interview with the parents by means of the M-CHAT-Follow-up.

After 48 months of age, this assessment can be based on the Social Communication Questionnaire (SCQ).

In children and adolescents without co-occurring intellectual developmental disorder, this assessment can be based on the following questionnaires: Autism Spectrum Screening Questionnaire (ASSQ), Autism-Spectrum Quotient (AQ) and Social Responsiveness Scale (SRS-2).

The tools are presented in Appendix 3.

Referral or follow-up according to the results of the dedicated consultation

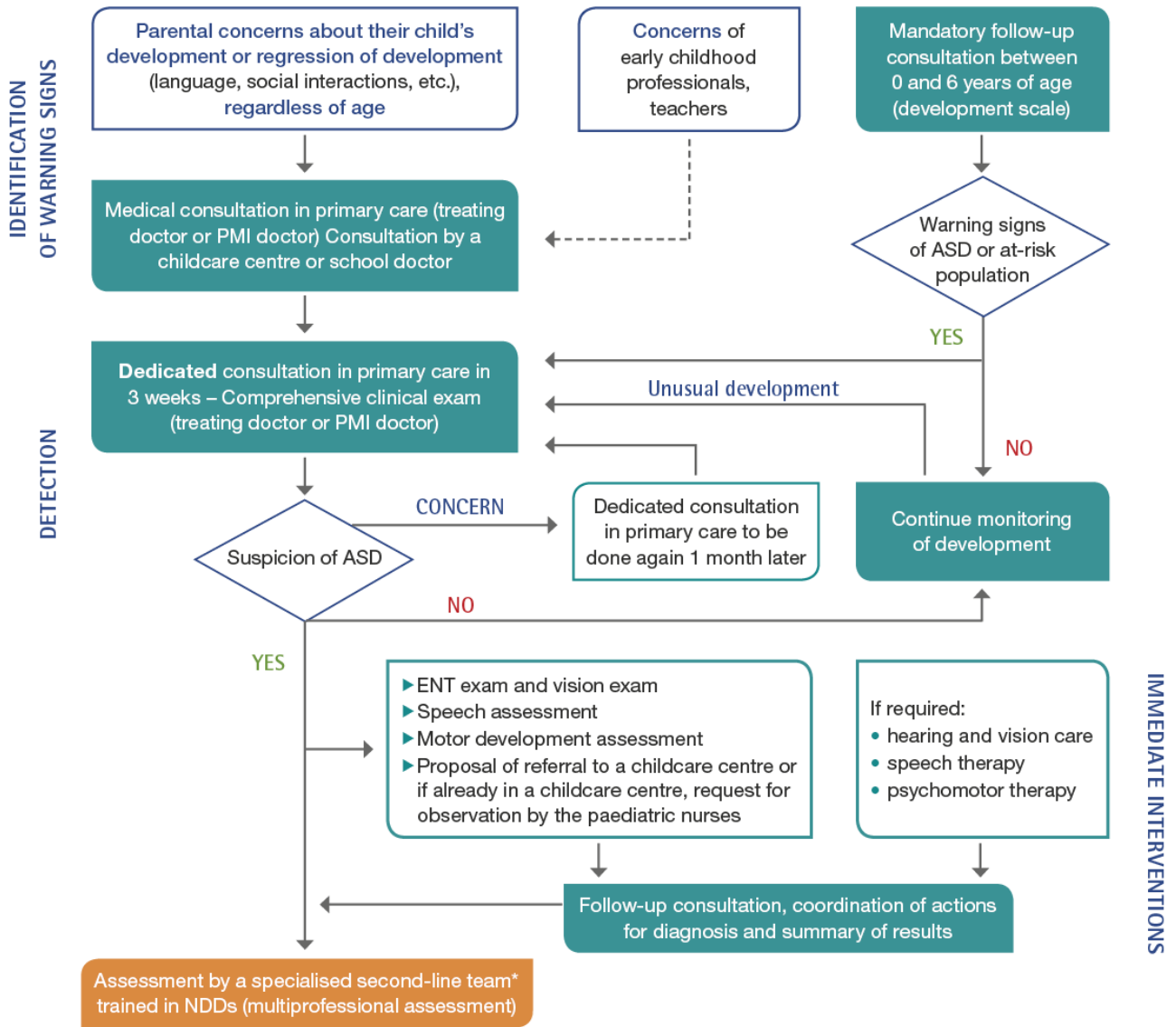
If the risk of ASD is confirmed during the dedicated screening consultation, the child should immediately be referred to a specialised neurodevelopmental disorders diagnostic consultation with a paediatric psychiatrist and/or a paediatrician.

Pending this specialised consultation with second-line professionals and results of the complete diagnostic process, the first assessments should be prescribed and local interventions should be implemented, especially in the area of communication (see chapter 3). The expected time between the detection of developmental abnormalities and the start of interventions (speech therapy, physiotherapy or psychomotor therapy, socialisation at a childcare facility) should be less than 3 months due to the developmental urgency in the young child.

In case of doubt about the result of the screening, especially when it does not confirm the parents' concerns, the child should undergo another close comprehensive assessment by his/her regular doctor within 1 month.

If the risk of ASD is not confirmed during the screening, the child's development should continue to be monitored through the child's regular medical monitoring, in particular the mandatory check-ups between ages 0 and 6 years.

⁶ M-CHAT: Modified Checklist for Autism in Toddlers.

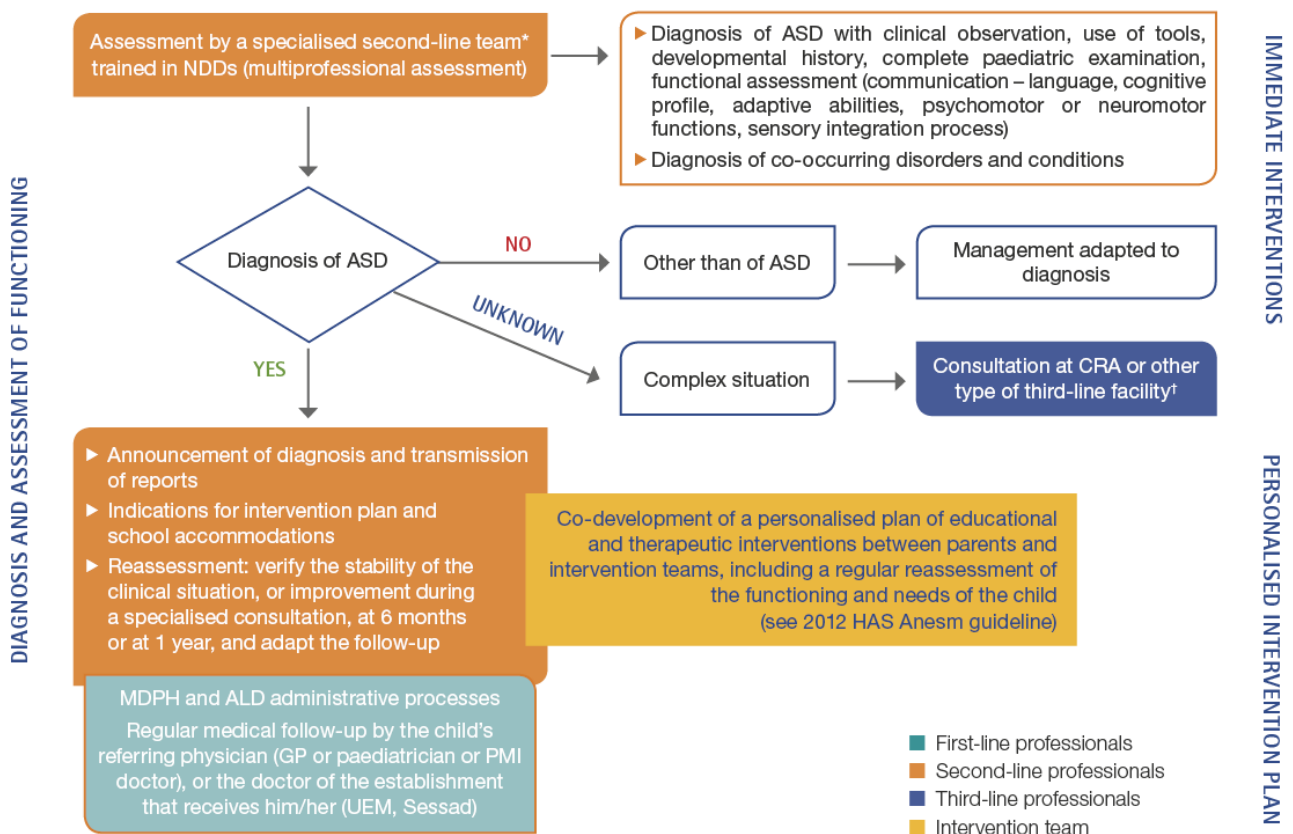


*Paediatric psychiatry teams (children's psychiatry departments including medico-psychological centres - CMP), paediatrics departments, centres for early medico-social action (CAMSP), medico-psycho-pedagogical centres (CMPP), network of specialised care in the diagnosis and assessment of autism or private practitioners coordinated by a doctor.

Figure 1. ASD risk screening pathway in children

2. Diagnosis and initial assessment of the child's functioning

The second step of the pathway of the child and his/her family is the diagnostic process to confirm whether or not the child has an ASD (see Figure 2). This process primarily involves second-line teams, in close collaboration with the doctor who provides the child's regular care. Any second-line facility can make diagnoses of NDD and then ASD, provided it has the required skills and makes the diagnoses according to the guidelines. A second-line team that is unable to make these diagnoses must refer the child as quickly as possible to a team capable of carrying out the diagnostic process.



*Paediatric psychiatry teams (children's psychiatry departments including medico-psychological centres - CMP), paediatrics departments, centres for early medico-social action (CAMSP), medico-psycho-pedagogical centres (CMPP), networks of specialised care in the diagnosis and assessment of autism or private practitioners coordinated by a doctor. † Professionals practising at autism resource centres (CRA) or at hospital centres for additional specialised opinions, namely in paediatric neurology, clinical genetics and medical imaging.

Figure 2. ASD diagnostic pathway in children

2.1 Diagnosis of ASD

The diagnosis of ASD is a clinical diagnosis.

An initial diagnosis of ASD is possible in children 18 months or older and should be made with reference to DSM-5 (pending ICD-11) (Appendix 1). Before this age, a diagnosis of neurodevelopmental disorder (NDD) is more appropriate due to the difficulties of a formal diagnosis and the heterogeneous and non-specific nature of early developmental trajectories.

This is a medical diagnosis based on a summary of information provided by the various allied health professionals and psychologists who contribute to the comprehensive clinical assessment of all aspects of development.

While it is necessary to use standardised tools for diagnosis, the diagnostic process cannot consist exclusively of them. Standardized tools are only an aide to clinical judgement (Appendix 4).

Due to the multidimensional nature of the clinical signs of ASD, the clinical approach should be multiprofessional (in particular including paediatric psychiatrists, paediatricians, psychologists and rehabilitation professionals) and should involve professionals who are experienced and specifically trained in neurodevelopmental disorders and other childhood disorders, and not only in ASD.

These professionals should coordinate amongst each other to ensure the consistency of the diagnostic process and to interpret its results.

The diagnostic process does not immediately fall under an autism resource centre (CRA) or another type of third-line facility⁷ (such as hospital departments dedicated to ASD); these facilities should preferentially treat the most complex situations (see Box 3). Instead, the diagnostic process should fall under a specialised local team⁸, namely a second-line team comprised of professionals specifically trained in neurodevelopmental disorders and autism spectrum disorder: paediatric psychiatry teams (children's psychiatry departments including medico-psychological centres - CMP), paediatrics departments, centre for early medico-social action (CAMSP), medico-psychopedagogical centre (CMPP), network of specialised care in the diagnosis and assessment of autism⁹ or private practitioners coordinated by a medical doctor.

Box 3. Criteria qualifying a complex situation

- Difficult to establish differential diagnosis
- Multiple co-occurring developmental, somatic, sensory, behavioural and psychiatric disorders
- Specific situations, such as: significant interference with psychiatric disorders or a severe or profound intellectual developmental disorder; clinical presentation that is muted or identified late; atypical clinical situations; etc.
- Disagreement on the diagnostic

► Monitoring points

As emphasised by the DSM-5, in the diagnosis of ASD “*The symptoms of ASD must be present in the early childhood period, (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)*”.

ASD can be particularly difficult to diagnose in children whose developmental age is under 18 months. Diagnosis is also challenging, regardless of age, in children and adolescents for whom there is no opportunity to describe early developmental history and in cases where psychiatric disorders, other neurodevelopmental or somatic disorders are associated with ASD.

⁷ See Instruction No. DGCS/SD3B/DGOS/SDR4/CNSA/2014/221 of 17 July 2014 on the national framework for detection, diagnosis and early interventions for children with autism or other pervasive developmental disorders provided for in the autism plan (2013-2017).

http://circulaires.legifrance.gouv.fr/pdf/2014/07/cir_38551.pdf

⁸ For example, a local autism diagnostic team (EDAP), autism diagnostic and early intervention team (EDIPA), regional unit for the assessment of neurodevelopmental disorders (URETND), etc.

⁹ For example, the ANAÏS network.

The literature¹⁰ suggests that over time a small number of children diagnosed with ASD may experience changes and no longer meet the diagnostic criteria for ASD, either through intrinsic progress or through compensation strategies. These changes are more likely to occur in children without co-occurring intellectual developmental disorder. Co-occurring disorders also present changes that must be detected and assessed.

2.2 Initial assessment of the child's functioning

An individualised clinical assessment should be performed, focusing on the different aspects of the child's development and functioning and on his/her environment (multidimensional evaluation); it should be specific, detailed and performed in varied contexts. This assessment falls under a coordinated process. It is performed by second-line teams.

The assessment is based on direct and indirect observations collected from those close to the child, especially his/her parents, but also from professionals at childcare centres and schools.

It also uses batteries of standardised tests appropriate for the child's age, developmental profile (e.g. language, motor skills, etc.), behaviour and testing context, giving preference to the validated tests and scales available (Appendix 4). It is also based on the areas and activities described in the International Classification of Functioning, Disability and Health (ICF)¹¹.

This assessment is able to establish, in collaboration with the child or adolescent, parents and professionals involved, the personalised plan of educational and therapeutic interventions¹².

This assessment should include at minimum the following items:

- *detailed developmental history*: date and reasons for the parents' first concerns; history of development including acquisition steps and development of motor skills, language, social interactions and communication, play, specific interests, behaviour; personal medical history (specify the course of the pregnancy, any use of medications and alcohol or drugs, the delivery) and family medical history; modes of socialisation, care and support;
- *verification of completion of standard screening tests* (hearing, vision¹³);
- *complete clinical paediatric exam* (weight, height, head circumference, neurological exam, etc.);
- *clinical observation*, while interacting with the child, of his/her social communication skills and behaviour to look for central signs of ASD with reference to the DSM-5 criteria. This observation can also be structured using standardised tools such as the CARS (Childhood Autism Rating Scale) or the ADOS (Autism Diagnostic Observation Schedule) or the ECA-R (*Échelle d'évaluation des comportements autistiques révisée* [autistic behaviours evaluation scale, revised]) (Appendix 4);

¹⁰ In 2010, the state of knowledge published by HAS indicated 80% to 96% diagnostic stability according to studies: HAS. Autism and other pervasive developmental disorders. State of knowledge excluding physiopathological mechanisms, psychopathological mechanisms and basic research. Summary prepared by formal consensus. Saint-Denis La Plaine; 2010.

In 2013, Fein *et al.* mentioned 17% of children no longer meeting the diagnostic criteria (introductory data). Fein D *et al.* Optimal outcome in individuals with a history of autism. *J Child Psychol Psychiatry* 2013;54(2):195-205

¹¹ The ICF child and youth version can be consulted on the WHO website:
http://apps.who.int/iris/bitstream/10665/81988/1/9789242547320_fre.pdf

¹² Refer to the HAS-Anesm 2012 recommendation on education and treatment interventions (*ibid.*).

¹³ In these children, sensory disorders lead to frequent amblyopia and strabismus, treatment of which is often compromised by the difficulty in getting them to accept wearing glasses or the penalization strategies that are part of rehabilitation. Limited cooperation also hinders examination and objective measurement of visual performance.

- *assessment of different dimensions of language and communication*, both nonverbal and pragmatic (e.g. joint attention and conversational skills) using available standardised tests;
- *assessment of the level of intellectual functioning and cognitive profile* (in terms of difficulties but also strengths and potentialities) using standardised psychometric tests available that are suitable to the child's chronological age and his/her other abilities, in particular language;
- *assessment of adaptive skills* the child displays in situations of daily life based on parental observations, in particular using the Vineland Scale;
- *assessment of psychomotor functions* including gross and fine motor skills using standardised tests suitable to the child's age and his/her other abilities;
- *assessment of sensory integration processes*.

This assessment must be available as soon as possible after the child has been referred, and must in no way delay the implementation of therapeutic interventions (e.g. speech therapy), educational interventions (e.g. structuring of the environment, early socialisation at a childcare facility) and pedagogical interventions (e.g. a school aide) on the basis of a provisional diagnosis (e.g. neurodevelopmental disorder with reference to the DSM-5).

The assessment of the child's functioning must be updated regularly so that the intervention plan can be updated in collaboration with the parties involved, especially the parents. The methods of subsequent assessments are based on medical indications.

In consistency with the guideline on interventions in children and adolescents¹⁴, and with the parents' agreement, the report of this assessment of the child's functioning should be sent to the professionals in charge of implementing the educational and therapeutic interventions. For school accommodations, if the parents so wish, the report should be forwarded by them.

2.3 Diagnosis of co-occurring disorders

Co-occurring disorders are very common in ASD. Diagnostic and therapeutic consideration of these co-occurring disorders can greatly improve the quality of life of affected children and their loved ones.

These disorders include:

- disorders or conditions that may affect the functioning of the child with ASD:
 - other neurodevelopmental disorders (intellectual development disorder, language disorder, attention deficit disorder, developmental coordination disorder [DCD]),
 - sensory disorders (deafness, low vision),
 - disruption of major physiological functions (eating and sleep behaviour),
 - psychological disorders (anxiety, depression, etc.),
 - neurological disorders: (epilepsy, neuromotor disorder [fatigability or paralysis, ataxia, abnormal movements]),
 - somatic condition: dental, hormonal, cardiac, gastrointestinal, metabolic, etc.

Careful screening for these co-occurring disorders is part of the "functional diagnosis", i.e. analysing "how" the child is functioning. These disorders should be taken into account in the assessment of the severity of the child's support needs;

¹⁴ HAS, Anesm. Autism and other PDDs: coordinated education and treatment interventions in children and adolescents. Saint-Denis La Plaine; 2012. http://www.has-sante.fr/portail/jcms/c_953959/fr/autisme-et-autres-troubles-envahissants-du-developpement-interventions-educatives-et-therapeutiques-coordonnees-chez-lenfant-et-ladolescent

- neurobiological vulnerability factors¹⁵ that may disrupt neurodevelopment and contribute to the emergence of cognitive disorders in children with ASD:
 - risk factors such as significant prematurity, prenatal exposure to drugs or alcohol, a cerebrovascular or traumatic injury or an infection (meningitis, encephalitis, etc.),
 - neurobiological determinants such as chromosomal or genetic abnormalities (several hundred are currently listed),
 - some of which have a *strong determinism* in the occurrence of an NDD (e.g. fragile X syndrome, 22q13/SHANK3 gene deletion, Bourneville tuberous sclerosis, dominant neomutations in many genes),
 - others that constitute a predisposing factor for an NDD in interaction with other genetic or environmental factors (e.g. numerous deletions/duplications discovered in chromosomal microarray analysis, rare gene variants).

Testing for these risk factors or these neurobiological determinants is part of the “aetiological diagnosis”. It tries to answer the question “why”, which worries parents despite the multiplicity of clinical expressions of ASD, and tries to provide information to the child and his/her parents. It can help to ensure a more targeted medical follow-up and thus avoid some additional disabilities associated with a given syndrome. The aetiological investigation does not always succeed. Even if it is comprehensive, the aetiological diagnosis can remain “undetermined”, either because the cause is unknown to date, or because the determinism is too multifactorial to be deciphered. This situation is especially common in ASD without intellectual developmental disorder (IDD).

Screening for co-occurring disorders should be routine, with monitoring in case of emergence of problem behaviours, and should be based on a family interview and the following assessments:

- family interview including:
 - history of the pregnancy and delivery (pre-and peri-natal problems including maternal illnesses and use of medications, especially valproate, or drugs or alcohol during the pregnancy, foetal ultrasound abnormalities and obstetric complications),
 - early developmental history with chronology of development, looking for a sense of developmental regression (especially of language or sociability),
 - the child’s personal medical history (medical or surgical problems, epilepsy, etc.),
 - other co-occurring disorders or conditions of the child (hyperactivity, anxiety, Tourette syndrome, obsessive compulsive disorder and depression),
 - family history (autism or ASD, intellectual developmental disorder, language disorders, congenital anomalies, recurrent miscarriage, perinatal death, depression, epilepsy, obsessive-compulsive disorder [OCD]),
 - sleep or eating disorders;
- comprehensive routine clinical assessment including:
 - general exam: height, weight and nutritional status, with interpretation of growth curves,
 - neurological examination, including an analysis of the head circumference growth rate (from the health booklet), and an observation of the child with particular attention to the quality of transfer, getting up from the ground, walking, fine motor skills of both hands, ocular motor function and orofacial praxis as well as muscle tone of the axis and limbs,
 - morphological examination for morphological abnormalities (face, skin, extremities, organs or other);
- use of specialised consultations, including:

¹⁵ ASDs are often multifactorial in origin, with risk factors that may be genetic, acquired pre- or post-natal (exposure to drugs or alcohol, infections, premature birth, etc.) or environmental, whose complex and still poorly defined interaction leads to the disorder, without assuming an exclusive deterministic link of a single causal factor. These neurobiological vulnerability factors underlie the emergence of an ASD even if they are not always identified in an affected child.

- ▶ vision (ophthalmological and orthoptic) exam and hearing test,
- ▶ routine proposal of a medical genetics consultation, especially for ASD co-occurring with an intellectual developmental disorder, a morphological abnormality or any clinical sign suggestive of an underlying genetic disease, and for any request for family genetic counselling, regardless of the form of ASD,
- ▶ paediatric neurology consultation in case of prematurity, intrauterine growth restriction, perinatal history, atypical clinical signs, motor disorder, developmental regression, abnormality in head circumference growth or in the neurological examination, or in case of an acute neurological episode: epileptic seizure, abnormal movements (excluding stereotypies), disorder of consciousness, excessive fatigability, etc.

To the extent possible, these clinical assessments or consultations are carried out by a local specialist, except for the medical genetics consultation, which is only accessible at a healthcare organisation (primarily university hospitals).

No routine test or paraclinical examination is recommended to diagnose ASD; these tests are done in case of a presenting symptom suggestive of a co-occurring disorder or a differential diagnosis. They are performed and interpreted by third-line professionals. The prescriptions guided by the previous examinations are as follows:

- EEG with technique adapted to best practice guidelines according to age;
- cerebral magnetic resonance imaging (MRI) with spectroscopy. The MRI enables a cause of ASD (creatinine deficit) or a tumour lesion or malformation associated with the ASD to be diagnosed. The imaging sequences used are specific to ASD¹⁶ and use of sedation is common¹⁷; therefore, this MRI must be performed at centres accustomed to performing MRIs on these patients¹⁸;
- other (electrophysiology, genetic testing, radiological assessments of malformations, etc.);
- neurometabolic assessments and, if possible, consultation at a reference centre for hereditary metabolic diseases.

As part of the testing protocol, other investigations in addition to those recommended as part of the diagnosis may be proposed; these investigations depend on the testing protocols.

2.4 Differential diagnosis

The differential diagnosis is based on a multidimensional and multiprofessional assessment. Most of the diagnoses commonly associated with autism may constitute a differential diagnosis, aside from selective mutism and social communication disorder, which are exclusive diagnoses. The main differential diagnoses of ASD in children are:

- sensory disorders (deafness and blindness) when they co-occur with behavioural disorders or interpersonal disorders;
- states of marasmus in a context of severe emotional deprivation and reactive attachment disorder; at times, the associated social relation problems may appear at first glance to be similar to those of ASD;
- communication disorders including language disorder and social (pragmatic) communication disorder. In some language disorders, children may have communication problems and secondary socialisation difficulties. Social (pragmatic) communication disorder involves a change in social communication and social interactions, but it does not involve behavioural

¹⁶ Recommended sequences: 3D T1, T2 and FLAIR coronal slices perpendicular to the hippocampus, T2 and FLAIR axial slices, diffusion axial slices and spectroscopy in the deep grey matter. Optional sequences: intravenous injection of contrast product in case of abnormalities in the previous sequences.

¹⁷ Drug sedation specific to ASD. Use of general anaesthesia is rare.

¹⁸ Paediatric university hospitals, for example.

problems or restricted and repetitive interests. Social (pragmatic) communication disorder and ASD rule each other out;

- global developmental delay and intellectual developmental disorder without ASD: intellectual developmental disorder is supported as a diagnosis when there is no difference between the level of sociocommunicative skills and the developmental level of other intellectual skills;
- attention-deficit/hyperactivity disorder (ADHD) due to attention disorders which can also be present in ASD;
- social anxiety disorder (social phobia) which has social withdrawal and the preference to be alone in common with ASD; however, the language and communication delay present in ASD is not found in social anxiety;
- some forms of epilepsy such as Landau-Kleffner syndrome, which involves the onset of loss of language (both expressive and receptive) associated with epileptic seizures in children 3 to 7 years of age;
- selective mutism: the child has appropriate social skills in some situations and in situations where he/she is mute, social reciprocity is not impaired. Selective mutism and ASD rule each other out;
- Rett syndrome, which can involve a change in social interactions during the regression phase between 1 and 4 years of age.

In older children and adolescents, the other main differential diagnoses of ASD are:

- obsessive compulsive disorder (OCD) which can involve stereotypies and restricted interests;
- early-onset schizophrenia, which can include a prodromal phase during which social impairments as well as restricted interests and atypical beliefs may emerge.

3. Procedures to follow from detection to diagnosis - Pathway

The following recommendations are summarised in a diagram in Appendix 6.

3.1 From identification of signs to diagnosis

In case of parental concern about their child's development, especially his/her language and communication and social interactions, the child should immediately undergo a dedicated consultation in primary care with a general practitioner (GP), a paediatrician or a PMI doctor. If this consultation does not allow a conclusion to be reached, the child should be assessed again in 1 month. In cases where, despite persistent parental concerns, the general practitioner or paediatrician does not confirm these fears, the parents should be free to seek a second opinion. The doctor who performed the first assessment then needs to provide his/her medical observations in writing to facilitate a second assessment.

The dedicated consultation in primary care includes a comprehensive clinical assessment of the child's development and, if ASD warning signs are identified, the plan to implement the actions listed below and start targeted interventions right away in case unusual development is confirmed:

- referral to an ENT for a hearing test and to an ophthalmologist or orthoptist for a vision test, with appropriate testing;
- prescription (regardless of age) of a communication and language assessment by a speech and language therapist, possibly specifying "with rehabilitation if necessary";
- prescription of an assessment of motor development by a psychomotor therapist, physiotherapist or occupational therapist in cases where functional difficulties have been observed in the areas of gross and/or fine motor and praxis skills;
- proposed regular or urgent referral of young children to a childcare centre¹⁹. If the child is already in a childcare centre, request for observation by paediatric nurses and/or early childhood educators and transmission of these observations, with the agreement of the parents;
- follow-up consultation, coordination of actions for diagnosis and summary of results for transmission to a second-line team.

At the same time, the child is immediately referred to a specialised second-line team trained in NDDs to carry out a multidimensional and multiprofessional assessment (see recommendations above).

Use of an autism resource centre (CRA) or another third-line facility should be considered in complex situations (see Box 5).

With the agreement of the parents, the child's regular doctor should be informed of assessments carried out in relation to rehabilitation, socialisation, progress observed, etc. The child's regular doctor should retain his/her position as the contact person in the child's follow-up, in particular to coordinate the diagnosis of possible subsequent co-occurring disorders. This doctor should handle, in connection with the specialised second-line teams, any administrative work related to the regional home for the disabled (MDPH) and chronic condition (ALD) processes. The latter in particular remain the responsibility of the treating physician. This coordination and these exchanges of information are essential to allow the rapid and suitable implementation of interventions for children and families.

¹⁹ In France, *établissements d'accueil des jeunes enfants* (EAJE) [childcare centres] are traditionally called "*multi-accueil*" and include *crèches*, *haltes-garderies*, etc.

► Specific situations

- If the PMI or school doctor is directly asked by the parents or the child's teachers about concerns for the child's development or learning, after speaking with the child and his/her parents in consultation, the doctor should refer them to the child's regular doctor.
- If the parents are not concerned despite the concerns of the child's regular doctor (or the team at the childcare centre), or if the parents do not understand their concerns and do not immediately agree to undertake a diagnostic process with a second-line team, a graduated approach should be used. This approach should involve monitoring by the first-line doctor and assessments by private allied health professionals, to allow the parents to gradually accept the situation, especially if the signs persist or worsen as the child develops.

3.2 Territorial organisation

Significant differences between territories are evident in the organisation of care pathways; the effectiveness of these pathways depends on local resources in terms of provision of care and also the direction taken by some facilities. There is sometimes a lack of visibility of existing resources for users, and there are also inequalities in access to diagnosis and care.

This observation should be taken into account in the territorial activities carried out by each ARS. In particular, the ARSs are invited to initiate a dialogue at the territorial level between the parties involved to discuss the best way to organise the diagnostic pathway of the children involved.

3.3 Medical follow-up and reassessment

The initial diagnosis of ASD should lead to regular medical monitoring of the child in the various dimensions of his/her health and his/her needs by the child's regular doctor, in connection with the specialised second-line teams (see section 2.1).

Multiprofessional reassessments of the child's functioning and needs are required during his/her pathway due to the potentially dynamic and non-fixed nature of ASD, to enable the personalised plan of interventions to be readjusted as needed. As a reminder, the diagnosis of ASD must be re-examined.

4. Announcement of the medical diagnosis and information for families

Announcement of the medical diagnosis is mandatory according to the medical code of ethics²⁰. If possible, this should be done in the presence of both parents, at a dedicated consultation with doctor (paediatric psychiatry, paediatrics or paediatric neurology, trained in the field of ASDs) and, if needed, another professional.

For announcement of the diagnosis, pending ICD-11, use of the term autism spectrum disorder (ASD) with reference to the DSM-5 is recommended.

As a reminder, the term infantile psychosis is inappropriate for the diagnosis of any form of autism. If the child has received a diagnosis that is not referenced in ICD-10 or the DSM-5 (such as infantile psychosis, progressive disharmony), a process to update the diagnosis as knowledge is updated can be proposed to the parents.

The diagnostic process is progressive, graduated, takes place over a variable duration, and is adapted to needs and requests of the parents and child, to arrive at the announcement of the diagnosis. The implementation of interventions can start even before all of the initial diagnostic assessments have been completed, as soon as a developmental disorder is observed²¹.

The announcement of an initial diagnosis of ASD is carried out based on multiprofessional assessments by the doctor who coordinates the process.

Before this step and while the diagnosis of ASD has not yet been confirmed, a provisional diagnosis of neurodevelopmental disorders should be made, accompanied by a functional diagnosis specifying the functional impairments or disabling health disorders, to allow interventions to be implemented and rights to be established with the regional homes for the disabled (MDPH) and National Health Insurance (chronic condition [ALD] protocol).

Announcement of the diagnosis of ASD²² should also focus on the diagnosis of possible co-occurring disorders, and shed light on the child's functioning by highlighting his/her skills, potentialities and difficulties. This perspective is based on the assessments carried out by doctors, psychologists and allied health professionals who have identified and evaluated this functioning in the various areas of the child's development.

The information provided during the announcement also includes current knowledge of what autism is and how it is likely to affect the child's development and functions; it also covers the risk of autism in siblings, along with the possibility of a referral to a clinical genetics consultation for aetiological genetic testing.

The announcement of the diagnosis must be associated with indications for development of a personalised plan of educational and therapeutic interventions²³, and for school accommodations adapted to the needs and demands of the child and his/her family, as well as their priorities and

²⁰ "Article 35 (Article R.4127-35 of the French Public Health Code). A doctor owes to any patient that he examines, advises and treats, honest, clear and appropriate information about his state of health and the investigations and treatment he proposes. Throughout the patient's illness, the doctor should tailor his explanations to the patient's personality and do his best to ensure that they are understood. However, a doctor must respect a patient's request not to be informed of a diagnosis or a prognosis, unless others are in danger of contamination." <https://www.conseil-national.medecin.fr/sites/default/files/codedeont.pdf>

²¹ Refer to the following best practice guideline: HAS, Anesm. Autism and other PDDs: coordinated education and treatment interventions in children and adolescents. Saint-Denis La Plaine; 2012. http://www.has-sante.fr/portail/jcms/c_953959/fr/autisme-et-autres-troubles-envahissants-du-developpement-interventions-educatives-et-therapeutiques-coordonnees-chez-lenfant-et-ladolescent

²² The medical diagnosis, established during the multiprofessional diagnostic process, corresponds to the nosological diagnosis, in reference to the DSM-5, supplemented by the functional diagnosis.

²³ Refer to the HAS-Anesm 2012 best practice guideline (*ibid.*)

preferences. This personalised plan of educational and therapeutic interventions with the parents and the child is developed after the announcement, and parents need to be supported during this transition period between the end of the diagnostic process and the effective implementation of the intervention plan co-developed with families.

Consideration should be given to the parents' usual needs for information as well as their needs for support with the administrative processes in terms of the resources available in the territory (childcare, personal care service, respite home, documentation services available in the territory including those of the autism resource centre [CRAs], associations for families and people with autism).

Recommendations, discussed with the parents, take into account the results of the assessment of the child's functioning, the resources available in the territory, and also the priorities and choices of the parents. To promote informed choices by families, families should be offered information or parental guidance sessions in the form of a psychoeducation or therapeutic education program.

In dialogue with parents, it is essential to determine how and when to give information to the child, and possibly his/her siblings. It is also appropriate to provide tools (such as informational brochures) to guide parents in their process of announcing the diagnosis to other friends and family members.

The parents should receive a written medical report making the medical diagnosis, including a summary of the clinical observations, the primary results of the assessments and recommendations for educational interventions, suitable school accommodations and therapeutic interventions. These recommendations aim to promote the child's development, inclusion, social participation and well-being. As a reminder, medical confidentiality does not apply to the child's legal representatives.

This report containing the information strictly necessary for the coordination or continuity of care or medico-social and social monitoring of the child should be routinely sent to the doctors and other professionals involved, in accordance with legal conditions and regulations for sharing of information²⁴.

Parents should be given the opportunity to ask questions at the time of the announcement, but also later after they have digested the information; also consider answering the questions of the child and any siblings.

The announcement of the diagnosis of ASD makes reference to "good announcement practices" (clarity and accessibility of the message, listening, articulation of educational and therapeutic proposals with the diagnosis, open prognosis).

► **Monitoring points**

Given the complexity and difficulties of the diagnostic pathway, additional attention is needed for families in situations of social or cultural vulnerability, or in cases where the parents themselves are disabled.

It is also necessary to be attentive to the needs of the family and to take an interest in their stress level and quality of life, in order to direct them towards assistance and support measures suitable for their needs and priorities (psychoeducation, therapeutic education, patient associations, psychological support, social assistance, etc.).

²⁴ Refer to Article L.1110-4 of the French Public Health Code, amended by the Law of 2016, and Articles R.1110-1 et seq. of the French Public Health Code (see Decree No. 2016-994 of 20 July 2016 on the conditions for exchange and sharing of information between healthcare professionals and other social and medico-social professionals and access to personal health information).

5. Conditions for adoption of recommendations and perspectives

5.1 Parental awareness

Highlight the important role of healthcare and childhood professionals within common law services (PMI, childcare centres, school medicine, mandatory health check-ups between 0 and 6 years of age, etc.) in spreading prevention messages about the expectations in usual development in terms of the chronology of acquisition of motor, language and school skills, in particular based on the health booklet.

5.2 Information and training for professionals

Update the training of healthcare professionals on the pathway of the child and his/her family, from detection to diagnosis, in order to reduce the deviation between recommended practices and practices actually implemented, which are sometimes quite removed from international standards.

Broadly disseminate the benchmarks and tools for monitoring the child's regular development and the warning signs of ASD with healthcare professionals, as well as professionals in early childhood, social sectors (child protection) and medico-social sectors, and teachers, in order to make all first-line professionals (healthcare and non-healthcare professionals) aware of the ordinary development of the child as well as identification of these warning signs.

Propose that the doctors who perform the comprehensive assessment of the child's development have specific training.

Train the different professionals on the use of the tools that they are likely to implement, based on their mode or place of practice:

- tools for monitoring the normal development of the child for first-line non-medical professionals (see Appendix 2);
- tools for detecting neurodevelopmental disorders and ASD for first-line doctors or teams ensuring the regular follow-up of the child, general practitioner, paediatrician, PMI doctor (see Appendix 3);
- tools for diagnosis and assessment of the child's functioning for local diagnostic teams (second-line) and complex diagnostic teams (third-line) (see Appendix 4 and Appendix 5).

Raise awareness among professionals regarding:

- good communication between each other;
- the quality of exchanges between professionals, children and their families.

5.3 Dialogue with supervisory authorities in the context of the establishing of objectives and resources contracts

The supervisory authorities (ARS) are encouraged, in the context of the 4th autism plan, to consult with the actors on the ground to:

- organise pathways from detection to diagnosis within each territory, at an infra-departmental level, and to define the roles of the different actors in the region (first-line, second-line and third-line professionals);

- jointly set achievable goals in terms of better access for children to be able to receive a diagnosis of ASD in the shortest possible time, taking into account the real situation of the services available in each territory with regard to all the activities of the facilities involved;
- negotiate a budget for the purchase of tools for detection, diagnosis or assessment of the child's functioning.

Implementation of a structured network and a training of first-line professionals (awareness of NDDs, detection, comprehensive clinical assessment) seems to be a prerequisite for reducing delays in access to the diagnosis.

5.4 Specific pricing system for long or very complex consultation

Propose a specific pricing system for follow-up and coordination consultations performed by the child's regular doctor under chronic condition (ALD) protocol for an ASD, based on the model of long and complex consultations²⁵ or follow-up consultations of a child with a serious chronic condition or a severe neurosensory disability who requires regular monitoring²⁶.

5.5 Cohort follow-up

Propose implementing cohort follow-up through registers, in particular on ASD, in order to collect and analyse epidemiological information related to its frequency and its spread (incidence and prevalence).

Continue research on ASD risk factors to acquire knowledge about the origin of this syndrome, evaluate the care situation and provide framework conditions, preventive measures and plans for medical follow-up and social and medico-social support that will be needed in the future.

Specify the characteristics and needs of girls with ASD, to confirm or disprove questions currently raised about a possible under-diagnosis of girls with ASD.

²⁵ Long and complex consultations have a special pricing system in France for patients with certain chronic conditions. These consultations are performed by the treating doctor, for example at the patient's home, in the presence of the usual caregivers.

²⁶ In 2017, the specific pricing system is reserved for paediatricians (Decree of 20 October 2016 approving the national agreement organising the relations between the private practice doctors and the National Health Insurance signed, on 25 August 2016).

Appendix 1. Autism spectrum disorders: diagnostic criteria of the DSM-5

This appendix reproduces the diagnostic criteria of the DSM-5, according to the American Psychiatric Association. Autism spectrum disorders. In: American Psychiatric Association. DSM-5. Diagnostic and statistical manual of mental disorders. Fifth edition. Arlington: APA; 2013.

Autism spectrum disorder is classified among neurodevelopmental disorders.

Diagnostic criteria 299.00 (F84.0)

A. Persistent deficits in social communication and social interaction across multiple contexts:

1. Deficits in social-emotional reciprocity.
2. Deficits in nonverbal communicative behaviours used for social interaction.
3. Deficits in developing, maintaining and understanding relationships.

Specify current severity: severity is based on social communication impairments and restricted, repetitive patterns of behaviour. The severity is coded in three levels (level 1: requiring support; level 2: requiring substantial support; level 3: requiring very substantial support).

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects or speech.
2. Insistence on sameness, inflexible adherence to routines or ritualised patterns of verbal or nonverbal behaviour.
3. Highly restricted, fixated interests that are abnormal in intensity or focus.
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment.

Specify current severity: severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed the limited capacities, or may be masked by learned strategies later in life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur. To make comorbid diagnoses of autism spectrum disorder and intellectual disability, the social communication should be below that expected for general developmental level.

Specify if:

- with or without accompanying intellectual impairment;
- with or without accompanying language impairment;
- associated with a known medical or genetic condition or environmental factor;
- associated with another developmental, mental or behavioural disorder;
- with catatonia.

Appendix 2. Main tools for monitoring the child's development

These tools are intended to be used by first-line professionals in order to detect the usual or unusual nature of a child's development and in particular possible ASD warning signs.

► Early assessment of different areas of development: baby-test and other scales

Tool	Age	Calibration	Organisation	Author	Access to resources
<p><i>Échelle de développement psychomoteur de la première enfance</i> [Brunet-Lézine scale of early childhood psychomotor development] BL-R</p>	2 to 30 months	+ 1,000 babies Quotient of overall development and by domain	4 domains: posture, coordination, language and sociability	Brunet and Lézine, 2001	Paid
<p>Denver Developmental Screening Test (DDST)</p>	Birth-6 years	French version 1,000 children % of success	4 domains: motor skills, language, fine motor skills, social contact 105 items	Frankenburg 1967, 1992	Free access (AFPA website)
<p>Simplified Gesell test</p>	11 age ranges, from 4 weeks to 5 years	Pass/fail response	4 domains: motor skills, cognition, language and social development	Simplified version of the Gesell scale, 1919	Free access Simplified test: http://fmc31200.fr/ee.fr/MG-liens/Pediatrie/test_Gesell.pdf Complete test: http://www.cofemer.fr/UserFiles/File/EchellePed1_3.pdf
<p><i>Inventaires français du développement communicatif</i> [French Communicative Development Inventories] (IFDC)</p>	Progress of scores at 12, 18 and 24 months	By percentile (from 10 th to 90 th)	Assessment of communicative gestures and lexicon in comprehension and production	Adaptation of the MacArthur Bates scales (MBCDI) 1991, 1998	Free access (websites of the Ministry for Solidarity and Health and AFPA)

Appendix 3. Main tools for detecting a risk of ASD

These tools are intended to be used by first-line professionals in order to contribute to the assessment of the risk of ASD as part of detecting the risk of ASD. This list is not exhaustive; the tools proposed are those that are best validated and available in French.

► In young children

Tool	Authors	Scale	Age	Access to resources
Modified Checklist Autism for Toddlers M-CHAT	Baron-Cohen, 1992 Robins, Fein and Barton, 2001, 2009	23 items Yes/no answer Risk score (0-2), (3-7) and (8-20)	16-30 months	Free access online http://mchatscreen.com/wp-content/uploads/2015/05/M-CHAT_French_v2.pdf
Modified Checklist Autism for Toddlers Revised/Follow-up M-CHAT-R/F	Robins, Fein and Barton, 2009 Baduel, 2016	Two-step tools 20 items Pass/fail response	18-24 months	Free access online http://mchatscreen.com/wp-content/uploads/2015/05/M-CHAT-R_F_French.pdf
Quantitative Checklist for Autism Q-CHAT	Allison <i>et al.</i> , 2012	25 items 5-point severity scale (0-4)	18-24 months	Free access online https://www.autismresearchcentre.com/arc_tests/
Social Communication Questionnaire SCQ	Rutter <i>et al.</i> , 2003	40 items 2 versions: Lifetime and current behaviour	From 4 years of age with a mental age above 2 years	Paid

► In children and adolescents without intellectual developmental disorder

Tool	Authors	Administration	Scale	Age	Access to resources
Autism Spectrum Screening Questionnaire ASSQ	Ehlers, Gillberg, Wing, 1999	Parents, teacher or person who knows the child well	27 items 3-point scale Threshold score of 20	Children and adolescents	http://scatn.med.sc.edu/screening/ASSQ.pdf
Autism-Spectrum Quotient AQ	Baron-Cohen <i>et al.</i> , 2001	Self-administration	50 items 4-point rating French version threshold score of 26	12-15 years	https://www.autismresearchcentre.com/arc_tests https://psychology-tools.com/autism-spectrum-quotient/ French version: http://www.cra-rhone-alpes.org/spip.php?article1693&calendrier_mois=06&calendrier_annee=2017
Social Responsiveness Scale SRS-2 (Second edition)	Constantino and Gruber, 2005, 2012, 2015	Parents and/or teachers	65 items 15-20 minutes DSM-5 compatible	2.5 years to adult	Paid (translation in process of validation)

Appendix 4. Main tools for diagnosing ASD and evaluating its severity

In addition to the criteria of the DSM-5 (see Appendix 1), to allow the diagnosis of ASD to be made and to provide an indirect indication of the severity of the ASD based on the assistance required for certain acts of daily living, the following tools used by second-line and third-line professionals contribute to the diagnostic process for identification of an ASD (ADI-R and ADOS-2) and evaluation of its severity (CARS-2, ECA-R and ECA-N).

This list is not exhaustive; the tools proposed are those that are best validated and available in French.

Professionals must have a good knowledge of the clinical signs of autism and regular practice with people with autism, acquired either during their initial training or during specific continuing education.

► Tools contributing to the diagnosis of ASD

	ADI-R Autism Diagnostic Interview
Authors	Developed by Le Couteur <i>et al.</i> (1989), then reorganised by Lord (1989, 1994, 2003). French translation in 1996, 2011
Form	Standardised structured interview
Psychopathological reference	Closely related to the criteria of ICD-10 and DSM-IV
Developmental reference	Schedule of ordinary development
Assessment	Allows the concerning behaviours to be described in terms of severity, degree of deviance, frequency compared to those of ordinary development
Prerequisite	Have a good knowledge of ordinary development and autism Mastery of interview and data collection techniques
Psychometric qualities	Good inter-rater reliability (for the total score, the score by domain and the different items) Good test-retest reliability (stability over time, little sensitivity to change) Good internal consistency Good correlations with CARS and ADOS
Administration	Interview lasting 1 1/2 to 3 hours depending on the clinical skills and experience of the examiner
Acceptability	Good acceptability by parents
Indication	The child must have a developmental level (a mental age) at least equal to 24 months Focus on the period of 4/5 years
Bias	Memorisation bias (Forward telescoping) for indicators related to a strong emotional charge Interpretation bias of first concerns
Organisation	93 items organised in 9 domains Calculation of the algorithm will concern 42
Rating	Considering the developmental age, the child's actual age and the level of verbal expression Two ratings: "currently" and "at any time of development" Two algorithms: current behaviours and diagnostic (Cut-off) Rating: 4-point severity scale (0=typical)
Prospective	Few significant modifications of the instrument planned in the coming years; however, need for validation according to changes of classification
Limitations	Not very sensitive before age 30 months
Access to resources	Paid

ADOS-2 Autism Diagnostic Observation Schedule, second edition	
Authors	Lord <i>et al.</i> , 1989, 1998, 2015 French translation
Form	Placement of child in semi-standardised scenarios
Psychopathological reference	References to DSM-IV-TR even though the notion of ASD is explicitly mentioned
Developmental reference	Schedule of ordinary development
Assessment	Allows the concerning behaviours to be described in terms of severity, degree of deviance, frequency compared to those of ordinary development
Prerequisite	Have a good knowledge of ordinary development and autism Agree to be filmed Skills to “stage” the child
Psychometric qualities	Good inter-rater reliability Good internal consistency Good inter-group validity Total score: good correlations with CARS and ADI and good measurement of the severity of the disorder
Administration	Administration time per module: 30 to 45 minutes
Acceptability	Good acceptability by the child and parents
Indication	Five modules: Toddler, 1, 2, 3 and 4 Cross-section of 2 criteria: actual age and level of language proficiency in production
Bias	Maximum cooperation of the child sought Familiarisation of the observer with the tool Asking parents in the absence of the child’s participation
Organisation	Ten situations (scenarios) per module: cross-section of 2 criteria (degree of structuring of the setting and complexity)
Rating	Videotaping the meetings Taking notes during the meeting Dual rating recommended Identifying the level of expressive language Calculation of an algorithm and conversion based on actual age Calculation of a severity score (comparison score)
Prospective	No indicators to date
Limitations	The material: purchase in the USA or, if transport is complicated and for standardisation purposes with respect to the properties of the toys (size, colour, function, etc.), interpretation must be adjusted A significant limitation of this tool has emerged since the new diagnostic criteria established by the DSM-5: a child can be considered to have an ASD according to the thresholds determined by ADOS-2 even though there is no disorder in the axis “stereotypies and restricted interests”. If this child does not have stereotypies or restricted interests, then he or she does not meet the DSM-5 diagnostic criteria for ASD.
Access to resources	Paid

► **Tools assessing the severity of the ASD**

Tool	CARS-2 Childhood Autism Rating Scale
Authors	Schopler <i>et al.</i> , 1980, 1988, Wellman and Love, 2010
Standards	Developed from several reference bases: Kanner, 1943; Creak, 1964; Rutter, 1978; Ritvo and Freeman, 1978; DSM III-R, 1987; DSM-IV-TR, 2000.
Psychometric qualities	Good internal consistency, good sensitivity, good specificity, good inter-rater reliability, good test-retest reliability; however, validity of structure to verify Coefficient of generalizability (which includes the child, the situation, the rater and their interactions) as satisfactory
Indication and contraindication	Subjects > 24 months The overall score is a good marker of severity But it is not a screening tool And it is not a tool for diagnostic purposes
Calibrations	1,606 subjects Specific rules for each group: 3 calibrations: 2-12 years, 13 years and +, and global T scores ($M = 50$ and $\sigma = 10$) and percentiles
Forms	Two versions: standard version (former CARS) and “high-level” version (functional language and $IQ > 80$), accompanied by a questionnaire for parents or caregivers as supplemental information for rating and interventions
Organisation	15 items: 14 items and 1 item of general impression In the high-level version: 15 items, including 4 new/classic version
Administration	5-10 minutes
Rating	4-point severity scale. Using the interim scores (1.5, etc.), 7-point scale. Range of scores: 15-60. Cut-off: 30-36 falls under moderate autism, > 36 under severe autism Given the frequency, intensity, singularity and duration of the behaviour Can be rated in group The rating depends on the variability of sample behaviours and the degree of structuring of the setting. For standardisation purposes, rate from video clips from semi-standardised situations over a period of 20 to 30 minutes.
Training	Training recommended
Access to resources	Paid (French version in Canada)

Tool	ECA-R <i>Échelle d'évaluation des comportements autistiques – version révisée</i> [Autistic behaviours evaluation scale – revised version]
Authors	Barthélémy <i>et al.</i> , 1997, J Autism Dev Disorders, 27:139-153
Standards	The ECA-R comes from the ECA (20 items): Barthélémy <i>et al.</i> , 1992, JADD, 22:23-31 and Barthélémy <i>et al.</i> , 1990, J Autism Dev Disorders, 20:189-204. Scales developed to supplement the CARS, the DSM-III-R and the ADI
Psychometric qualities	Factor structure: 2 main factors: “Interpersonal impairment” (13 items) and “Motor skills impairment” (3 items) The “Interpersonal impairment” score, which has an excellent internal consistency, measures the severity of the autism. Good inter-rater reliability Sensitivity: 0.74, specificity: 0.71
Indication and contraindication	Children up to 12 years of age Simplicity of use Precise measurement of the severity of the autism Sensitive to variations in behaviour over time Sensitive to changes induced by treatments and rehabilitation (McConachie <i>et al.</i> , 2015, <i>Health Technol Assess</i> , 19:1-506)
Calibrations	136 children with severe developmental disorders (DSM-III-R criteria), aged 20 to 139 months
Forms	Revised version
Organisation	29 items in its revised version
Administration	20 minutes.
Rating	5-point severity scale that measures the frequency and severity of “target” behaviours such as social withdrawal, verbal and nonverbal communication disorders, repeated behaviours, intolerance to change, paradoxical reactions to the environment, attention and perception disorders, etc. Rating by any trained professional at the autism clinic
Training	Training on clinical signs of ASD required
Access to resources	Paid

Appendix 5. Main tools for evaluating the child's functioning

The following tools make it possible to evaluate the child's functioning in the different areas of development. This list is not exhaustive; the tools proposed are those that are best validated and available in France.

They are used by second-line or third-line professionals, as part of the initial assessment of functioning during the diagnostic process or when updating coordinated personalised plans for educational and therapeutic interventions during subsequent follow-up of the child²⁷.

For these tests to be adapted to the specific situation of each child and for the interpretation of the results to consider these adaptations, especially in the case of poorly developed oral language, professionals must have a good knowledge of the clinical signs of autism and regular practice with people with autism; these skills can be acquired either during their initial training or during specific continuing education.

► Evaluation of intelligence in children with ASD: global standardised tests not specific to ASD

Language level	Test	Calibration French	Time	Organisation	Authors
Nonverbal	Snijders-Oomen nonverbal intelligence test SON-R	2.5-7 years Standard scores, $m = 10$ and $\sigma = 3$ and $M = 100, \sigma = 15$	> 45 minutes	6 subtests of 15 items Son-Performance Son-Reasoning	Tellegen, 1943, 1958, 1975, 1988
Nonverbal	Coloured progressive matrices CPM or (PM47)	1998, 1064 children 4 to 11.5 years old	20 minutes	Paper version 3 series 36 items total	Raven, 2008
Nonverbal	Coloured progressive matrices (board form) CPM-BF	> 4 years of age	20 minutes	3 series 36 items total	Raven, 2008
Nonverbal and verbal	Standard progressive matrices SPM or (PM48)	1938, 1998, 670 children 7 to 11.5 years old	20 minutes	5 series 12 items each	Raven, 2008
Nonverbal	Wechsler Nonverbal Scale of Ability WNV	4 years - 8 years Standard scores, $m = 50$ and $\sigma = 10$ IQ percentile	30 minutes	2 versions (2/4 items) Matrices, codes, assembly of objects, arrangement of images	Wechsler and Naglieri, 2009
Verbal	Wechsler Preschool and Primary Scale of Intelligence – Fourth Edition WPPSI-IV	Two calibrations 2.5 years - 3 years 11 months 4 years to 7.5 years	60 minutes	Shapes 7 and 15 subtests 3 scales (total index, main and supplemental indices)	Wechsler, 2014
Verbal	Wechsler Intelligence Scale for Children – Fifth Edition WISC-V	6 years to 16 years 11 months	60 minutes (shorter than WISC-IV)	15 subtests (including 3 new ones) Total scale and 5 indices: main and supplemental	Wechsler, 2016

²⁷ Refer to the HAS, Anesm guideline. Autism and other PDDs: coordinated education and treatment interventions in children and adolescents. Best practice guideline. Saint-Denis La Plaine; 2012. https://www.has-sante.fr/portail/upload/docs/application/pdf/2012-03/recommandations_autisme_ted_enfant_adolescent_interventions.pdf

► **Intelligences: severity of the intellectual developmental disorder**

“The various levels of severity [of the intellectual developmental disorder] are defined [by the DSM-5] on the basis of adaptive functioning and not IQ scores, because it is adaptive functioning that determines the level of supports required.”

Title	Vineland-II Vineland Adaptive Behavior Scale (VABS-II)
Authors	Doll, 1935, 1968; Sparrow, Cicchetti, Balla, 1965, 1984, 2005
Psychometric qualities	Good internal consistency, confirmatory factor validity, good discriminant validity Good correlations between the two forms Low correlations between IQ (Wechsler) and Vineland
Standards	American Association on Mental Retardation (AAMR, 2002), DSM-IV-TR (2000), CIF, 2001, 2011
Forms	Semi-structured interview not requiring the presence of the subject Two forms: interview and parent/caregiver
Organisation	Four functional domains (divided into 3 sub-domains): communication, daily life, social skills and physical activities, and problematic behaviours (internalised and externalised), and 383 items
Objectives	Assessment of activity limitations Measurement of severity of intellectual impairment Determine axes of intervention/compensation Developmental monitoring
American calibration	3,687 subjects from 44 states Birth-90 years
French calibration	2015 French version, ECPA Pearson 1,654 questionnaires and 310 control subjects
Administration	Between 30 and 60 minutes and 15 to 30 minutes for interpretation
Rating	3-point rating (2: activity is performed in a normal manner; 0: not performed) No right or wrong answers What the subject usually does and not what he/she would be able to do
Scores	Conversion of raw scores into standard scores by chronological and/or developmental age (sub-domains): global, by domain and sub-domain Composite total: $m = 100$ and $\sigma = 15$ Sub-domains: $m = 15$ and $\sigma = 3$
Prerequisite	Check the competence of the respondent and good investigator/respondent climate Interview experience for collection of data and interpretation of tests Define the relevant “developmental window” Training strongly recommended
Prospective	Vineland 3 released in the USA in 2016

► Clinical tests specific to ASD

Tests	Reference	Calibration	Administration	Organisation	Training	Author
Psychoeducational Profile PEP-III	Idea of emergence Developmental profile Educational intervention	2 years to 7 years Developmental ages	45 minutes to 1 hour 30 minutes 3-point rating 172 items	3 categories Communication and motor skills, inappropriate behaviour	Required	Schopler, 1979, 2004, 2008
Sensory Profile SP	Sensory processing, modulation, and behaviours Hyper-and hypo-reactions	3 years to 10 years 11 months 1,037 Americans 561 French	30 minutes for the long version 10 minutes for the short version 125 items	2 child versions: long and short	Required	Dunn, 2010
Social Cognitive Evaluation Battery SCEB	Positions: Piaget, Bruner and Fischer	4 months to 24 months (divided into 4 periods)	196 items	16 domains and 2 profiles: cognitive, socio-emotional	Required	Adrien, 2007
Early Social-Communication Scales ESCS	Communicative behaviours (Bruner and Bates) Fisher's neo-Piagetian theories	3 to 30 months Levels of development in the targeted domains	40 minutes 23 situations and 108 items	3 dimensions: Social interaction, joint attention and behaviour regulation	Required	Seibert and Hogan, 1982 Guidetti, Tourette, 2009
Imitation Scale IS	Coupling perception/ action Mirror neurons	Assessment of motor skills, means-goals relationships and synchrony	45 minutes 4-point rating 36 items	3 dimensions: spontaneous imitation, imitation on demand and recognition of being imitated	Required	Nadel, 2011, 2015
Test of Pretend Play TOPP	Substitution, attribution and reference of objects	Americans 1 to 6 years of age	45 minutes	2 versions: verbal (+ 3 years) and nonverbal	Required	Lewis and Boucher, 1998
Quality of life scale Par-DD-QoI	Impact of the developmental disorder on parental quality of life	590 parents of children with ordinary development 349 parents of children with unusual development	17 items 10 minutes	3 dimensions: Adaptive, emotional and total	-	Raysse, 2011
Aberrant Behavior Checklist ABC	Assessment of treatments in delayed developments	927 institutionalised individuals 5 to 58 years of age	58 items Rating of 0 to 3 (severity)	Factor structure in 5 factors	-	Aman, Sing, Steward and Field, 1985

► Assessment of psychomotor or neuromotor skills

Below are suggested, as possible examples, some tools for assessment of psychomotor functions, neuromotor functions or functions related to movement, which are not specific to ASD but which are regularly used with children with NDD.

Instruments	Author	Indication	Age	Organisation
<i>Batterie d'évaluation des fonctions neuropsychomotrices de l'enfant</i> [Assessment battery for neuro-psychomotor functions in children] NP-MOT	Vaivre-Douret, 2006	Assessment of sensory integration and neuromotor systems	4-8 years French standards Calibrated by sex, academic level and function 446 boys and girls	Items of qualitative and quantitative observation of 9 functions: tonus, global motor skills, laterality, manual praxis, tactile gnosis, hand-eye coordination, spatial orientation, rhythm, auditory attention
<i>Développement fonctionnel moteur</i> [Motor function development] DF-MOT	Vaivre-Douret, 1999	Evaluation of postural and motor development and prehension, hand-eye coordination	0 to 48 months French standards 123 children in longitudinal follow-up	Precise description of targeted and standardised behaviours
Movement Assessment Battery for Children M-ABC2	French adaptation: Marquet-Doléac, Soppelsa and Albaret, 2016	Evaluation of motor skills: delays and disorders	3-17 years old, in age brackets French standards 626 children	Three domains and 8 tests: manual dexterity, ability to aim and catch, static and dynamic balance
Concise Assessment Scale for Children's Handwriting BHK and BHK Ado	French version, Charles, Soppelsa and Albaret, 2004 and 2013	Early detection of dysgraphia and writing disorders	From <i>cours préparatoire</i> (CP) to <i>cours moyen 2e année</i> (CM2) 837 children From <i>sixième</i> (6 ^e) to <i>troisième</i> (3 ^e) 471 subjects French standards	Copying a 5-minute text Scale of 13 items

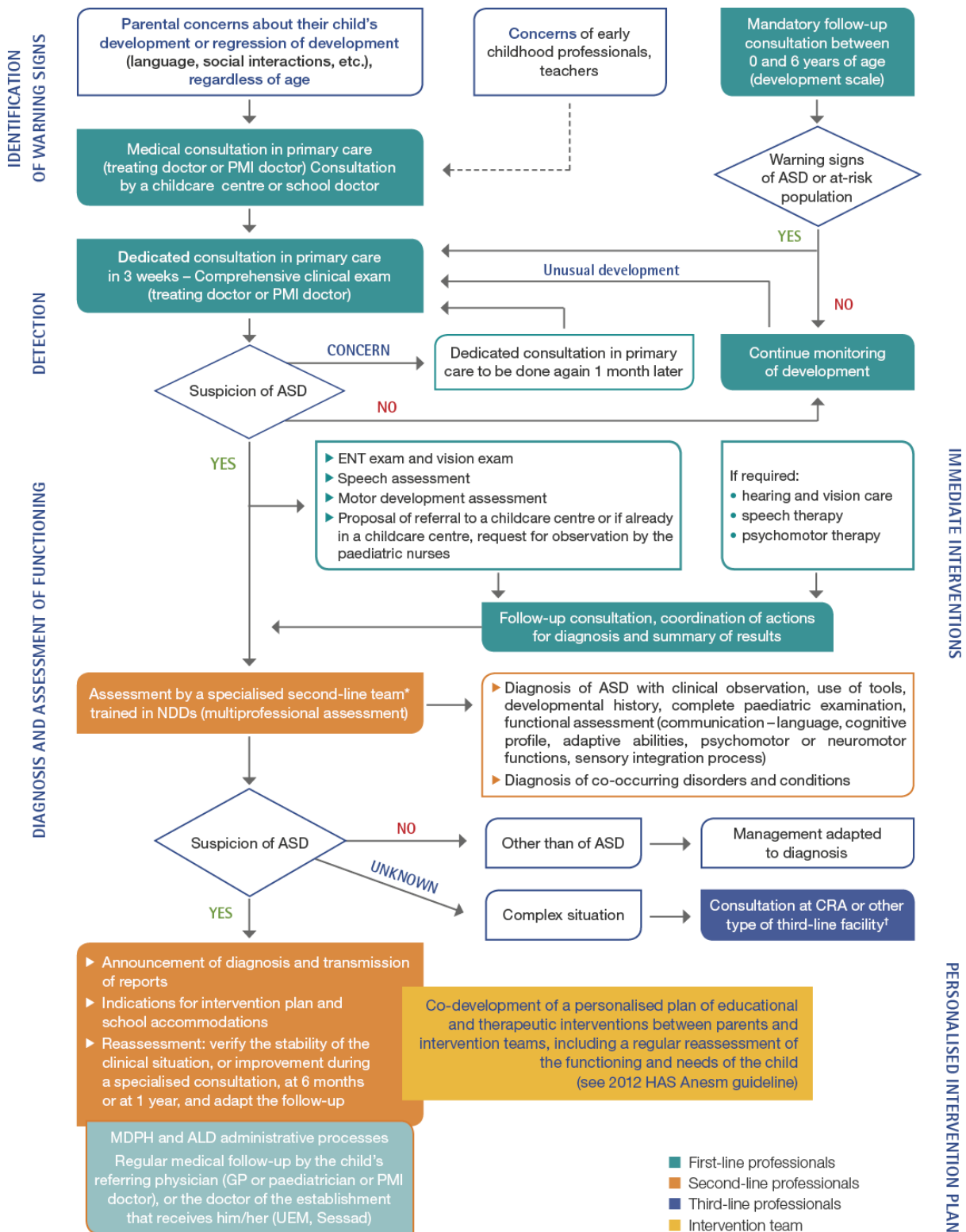
► Assessment of communication and language

Below are suggested, as possible examples, some tools for assessment of communication and language, as well as pragmatic and social skills. These tools are not specific to ASD, but are regularly used with children with NDD.

Tests	Authors	Assessment	Administration	Access to resources
<i>Nouvelles épreuves pour l'examen du langage</i> [New tests for language examination] N-EEL	Chevrie Muller; Piazza; Fournier and Rigoard, 2001	Complete assessment of language components (comprehension and production) Word-finding difficulties and difficulties accessing the lexicon	3 years 7 months to 8 years 7 months 17 subtests 2 protocols Form P (young children) and G (older children)	Paid
<i>Évaluation des stratégies de compréhension en situation orale</i> [Assessment of comprehension strategies in oral situations] O52	Khomsî, 1987	Oral language comprehension disorders in 52 statements	Scores calibrated for ages 3-7 years Immediate and overall comprehension	Free access online http://web.ac-reims.fr/dsden52/erco/m/documents/ash/tsa_tsl_dyslexie_dyscalculie/comment_se_servir_du_O52.pdf
Clinical Evaluation of Language Fundamentals CELF CDN-F	French version, Wigg <i>et al.</i> 2009	Reception and production skills Very sensitive to language difficulties	520 children: 4-8 years and 9-16 years 19 subtests including 4 for obtaining a fundamental language score - FLS	Paid
<i>Épreuve de compréhension syntactico-sémantique</i> [Syntactical semantic comprehension test] E.co.s.se	Lecocq Inspired by the TROG (Test for Reception of Grammar by Bishop, 1983)	Oral and written syntactical semantic comprehension test	4-12 years Oral calibration in 2,100 children; 20 minutes	Paid
Test of Pragmatic Language-2 TOPL-2	Phelps-Terasaki and Phelps-Gunn, 2007	Pragmatic skills and impairments	2 notebooks (6 years to 18 years 11 months) 45-60 minutes Standards	French translation available at CRAs
Peabody picture vocabulary scale EVIP	Dunn, Theriault-Whalen and Dunn, 1993	2 forms (A and B) and 175 boards each Canadian calibration on 2,028 children and adolescents	2 years 6 months to 18 years 8-15 minutes 170 items (indicate 1 picture out of 4)	Paid
Forerunners in Communication assessment tool COMFOR2 (also called ComVoor)	Verpoorten, Noens, and Van Berckelaer-Onnes, 2012	Recommendations on implementation of augmentative or alternative communication	No oral instructions. 45 minutes. 36 items of increasing complexity, organised into 5 series of 2 levels (sensory or	Paid

Tests	Authors	Assessment	Administration	Access to resources
			functional). Each item is a sorting, integrating or matching task.	

Appendix 6. Procedures to follow for diagnosis of ASD - Pathway



*Paediatric psychiatry teams (children's psychiatry departments including medico-psychological centres - CMP), paediatrics departments, centres for early medico-social action (CAMSP), medico-psycho-pedagogical centres (CMPP), networks of specialised care in the diagnosis and assessment of autism or private practitioners coordinated by a doctor. † Professionals practising at autism resource centres (CRA) or at hospital centres for additional specialised opinions, namely in paediatric neurology, clinical genetics and medical imaging.

Participants

At the start of the project, the following professional bodies and associations of patients and users were asked to offer experts, individually invited to the work and reading group. This request was made in parallel to a call for candidates published on the HAS website:

Association française de promotion de la santé scolaire et universitaire (AFPSSU) [French Association for Health Promotion at School and University]*

Association nationale des centres de ressources autisme (ANCRA) [National Association of Autism Resource Centres]*

Association nationale des équipes contribuant à l'action médico-sociale précoce (ANECAMSP) [National Association of Teams in Early Medico-Social Action]*

Collectif autisme [Autism Collective]*, including Autisme France [Autism France]*, Sésame Autisme [Sesame Autism], Autistes sans frontières [Autism without Borders], Pro Aid Autisme [Pro Aid Autism], Asperger Aide [Asperger Aid]

Collège de la médecine générale [College of General Practice]*

Collège infirmier français [French Nursing College], including the Association nationale des puéricultrices (ANPDE) [National Association of Paediatric Nurses]*

Collège national pour la qualité des soins en psychiatrie (CNQSP) [National Association for the Quality of Psychiatric Care]*

Conseil national professionnel de génétique clinique, chromosomique et moléculaire [National Professional Council of Clinical, Chromosomal and Molecular Genetics]*

Conseil national professionnel de pédiatrie (CNPP) [National Professional Council of Paediatrics]*, including the Société française de pédiatrie (SFP) [French Society of Paediatrics]*, the Association française de pédiatrie ambulatoire (AFPA) [French Association of Ambulatory Paediatrics]*, the Syndicat national des médecins de protection maternelle et infantile (PMI) [National Union of Doctors of Maternal and Child Welfare]*

* Bodies that offered names of experts

Conseil national professionnel de radiologie [National Professional Council of Radiology]*

Fédération française de psychiatrie (FFP-CNPP)* [French Federation of Psychiatry], including the Association des psychiatres de secteur infanto-juvénile (API) [Association of Child and Adolescent Psychiatrists], the Association française de thérapie comportementale et cognitive (AFTCC) [French Association of Behavioural and Cognitive Therapy], the Association scientifique de psychiatrie institutionnelle (ASPI) [Scientific Association of Institutional Psychiatry]*, the Fédération des CMPP (FDCMPP) [Federation of Medico-Psycho-Pedagogical Centres]*, the Société française de psychiatrie de l'enfant et de l'adolescent et des disciplines associées (SFPEADA) [French Society of Child and Adolescent Psychiatry and Associated Fields]*,

Fédération française des psychologues et de psychologie (FFPP) [French Federation of Psychologists and Psychology]*

Fédération française des psychomotriciens (FFP) [French Federation of Psychomotor Therapists]

Groupement national des centres ressources autisme (GNCRA) [National Grouping of Autism Resource Centres]*

Société française de neurologie pédiatrique (SFNP) [French Society of Pediatric Neurology]*

Union nationale pour le développement de la recherche et de l'évaluation en orthophonie (UNADREO) [National Union for the Development of Research and Assessment in Speech Therapy]*

► Working group

Prof. Amaria Baghdadli, paediatric psychiatrist, Montpellier – Co-chair

Dr Isabelle De Beco, general practitioner, Paris – Co-chair

Ms Natacha Marpillat, pharmaco-epidemiologist, Quimper – Project leader

Mr René Pry, university professor, psychologist, Villeneuve-Lès-Maguelone – Project leader

Ms Joëlle André-Vert, Saint-Denis – HAS project manager

Ms Muriel Dhénain, Saint-Denis – HAS project manager

Dr Maryse Bonnefoy, PMI doctor, Lyon

Prof. Frédérique Bonnet-Brilhault, paediatric psychiatrist, Tours

Dr Clément Charra, general practitioner, Ladoix-Serrigny

Prof. Anne Danion-Grilliat, psychiatrist, Strasbourg

Prof. Vincent Desportes, paediatric neurologist, Lyon

Dr Michel Gilot, paediatrician, Fontaine

Dr Dominique Girardon-Grichy, general practitioner, Montlignon

Dr Marie-Maude Geoffray, paediatric psychiatrist, Bron

Ms Virginie Gouby, psychomotor therapist, Saint-Lambert-des-Bois

Dr Domitille Gras, CAMSP doctor, paediatric neurologist, Paris

Dr David Grevent, paediatric neuroradiologist, Paris

Ms Géraldine Hilaire-Debove, speech therapist, doctor of language sciences, Fontaines-sur-Saône

Dr Laëtitia Lambert, clinical geneticist, Nancy

Dr Anaïs Ledoyen, paediatrician, Ajaccio

Dr Marianne Lenoir, school doctor, Mâcon

Mr Georgio Loiseau, patient representative, Poses

Ms Camille Moreau, patient representative, Parisot

Ms Sandrine Oblet, psychologist, Toulon

Dr François Pinelli, general practitioner, Apt

Mr Éric Romeo, psychomotor therapist, Olonne-sur-Mer

Ms Régine Scelles, university professor, psychologist, Nanterre

Dr François Soumille, psychiatrist, Marseille

Dr Maria Squillante, psychiatrist, Nantes

Ms Valérie Verot, patient representative, Brax

Ms Aurore Vinot, paediatric nurse, Bar-le-Duc

► Stakeholders

The following stakeholders were consulted for opinion:

Académie d'ophtalmologie [Academy of Ophthalmology], including the Société française d'ophtalmologie (SFOPH) [French Society of Ophthalmology]*

Actions pour l'autisme Asperger [Actions for Asperger Autism]*

Agence nationale pour l'évaluation et la qualité des établissements et services sociaux et médico-sociaux (Anesm) [French National Agency for the Evaluation of Quality of Medico-social and Social Services and residential facilities]*

Assemblée des départements de France [Assembly of Departments of France]

Association 4A [4A Association]*

Association Acanthe [Acanthe Association]

Association Asperger Amitié [Asperger Friendship Association]

Association Autisme Espoir vers l'école (AEVE) [Autism Hope towards School Association]*

Association de personnes autistes pour une autodétermination responsable et innovante (PAARI) [Association of Autistic People for Responsible and Innovative Self-Determination]*

Association des enseignants chercheurs de psychologie des universités (AEPU) [Association of University Psychology Research Instructors]

Association française de pédiatrie ambulatoire (AFPA) [French Association of Ambulatory Paediatrics]*

Association française de promotion de la santé scolaire et universitaire (AFPSSU) [French Association for Health Promotion at School and University]

Association française de thérapie comportementale et cognitive (AFTCC) [French Association for Behavioural and Cognitive Therapy]*

Association francophone de femmes autistes [French Association of Women with Autism]*

Association nationale des centres de ressources autisme (ANCRA) [National Association of Autism Resource Centres]

Association nationale des équipes contribuant à l'action médico-sociale précoce (ANECAMSP) [National Association of Teams in Early Medico-Social Action]*

Association nationale française des ergothérapeutes (ANFE) [French National Association of Occupational Therapists]*

Association Optim'Autisme [Optim'Autisme Association]

Association pour la promotion des pratiques fondées sur des preuves en psychopathologie du développement (AP4D) [Association for the Promotion of Evidence-Based Practices in Developmental Psychopathology]

Association pour la recherche sur l'autisme et la prévention des inadaptations (ARAPI) [Association for Research on Autism and Prevention of Maladjustments]*

Association pour la sensibilisation à la protection, l'éducation et la recherche sur l'autisme, et notamment le syndrome d'Asperger [Association for Awareness of Protection, Education and Research on Autism, including Asperger's Syndrome]

Association SOS Autisme [SOS Autism Association]

Association Spectre autistique troubles envahissants du développement international (SAtedI) [International Association for Autism Spectrum and Pervasive Developmental Disorders]*

Association Vaincre l'autisme [Overcoming Autism Association]

Agricultural Social Mutual Fund (CCMSA)*

National Salaried Workers' Health Insurance Fund (CNAMTS)

Collectif Autisme [Autism Collective], including Autisme France [Autism France]*, Sésame Autisme [Sésame Autism], Autistes sans frontières [Autism without Borders], Pro Aid Autisme [Pro Aid Autism]*, Asperger Aide [Asperger Aid]*

Collège de la masso-kinésithérapie [College of General Physiotherapy]

Collège de la médecine générale (CMG) [College of General Practice]*

Collège infirmier français [French Nursing College], including the Association nationale des puéricultrices (ANPDE) [National Association of Paediatric Nurses]*

Comité consultatif national des autistes de France (CCNAF) [National Advisory Committee of Autistic Persons of France]*

Comité de liaison et d'action des parents d'enfants et d'adultes atteints de handicaps associés (CLAPEAHA) [Liaison and Action Committee for Parents of Children and Adults with Associated Disabilities]

Comité interministériel du handicap [Inter-ministerial Committee on Disabilities]

Conférence nationale des présidents de CME/CHS [National Conference of Chairs of CME (institution medical committees)/CHS (specialised hospital centres)]*

Conseil national professionnel de psychiatrie [National Professional Council of Psychiatry], including the Collège national pour la qualité des soins en psychiatrie (CNQSP) [National College for the Quality of Psychiatric Care]*, the Collège national universitaire de psychiatrie (CNUP) [National University College of Psychiatry], the Fédération française de psychiatrie – Conseil national de psychiatrie (FFP-CNP) [French Federation of Psychiatry – National Council of Psychiatry]*, the Collège de pédopsychiatrie [College of Child and Adolescent Psychiatry]

Ministry of Health - Social Security Directorate* (DSS)

Ministry of Health - General Directorate of Health Care Supply (DGOS)

Ministry of Health - General Directorate of Social Cohesion (DGCS)

Ministry of Health* - General Directorate for Health (DGS)

Fédération des cliniques et hôpitaux privés de France – Psychiatrie (FHP PSY) [Federation of Private Clinics and Hospitals of France – Psychiatry]*

Fédération des CMPP (FDCMPP) [Federation of Medico-Psycho-Pedagogical Centres]*

Fédération française de génétique humaine (FFGH) [French Federation of Human Genetics]*

Fédération française de psychiatrie (FFP) [French Federation of Psychiatry], including the Association des psychiatres de secteur infanto-juvénile (API) [Association of Child and Adolescent Psychiatrists]*,

L'Association scientifique de psychiatrie institutionnelle (ASPI) [Scientific Association of Institutional Psychiatry], the Société française de psychiatrie de l'enfant et de l'adolescent et des disciplines associées (SFPEADA) [French Society of Child and Adolescent Psychiatry and Associated Fields], the Société de l'information psychiatrique (SIP) [Society of Psychiatric Information]*

Fédération française des psychologues et de psychologie (FFPP) [French Federation of Psychologists and Psychology]*

Fédération française des psychomotriciens (FFP) [French Federation of Psychomotor Therapists]*

Groupement national des centres de ressources autisme (GNCRA) [National Grouping of Autism Resource Centres]*

Organisation nationale des éducateurs spécialisés (ONES) [National Organisation of Specialised Educators]

Rassemblement pour une approche des autismes humaniste et plurielle (RAAHP) [Gathering for a Humanistic and Pluralistic Approach to Autism]*

Health and retirement Fund for independent workers (RSI)

Réseau Autisme Science [Autism Science Network]*

General Secretariat of ARS (ARS Pays de la Loire*, ARS Nouvelle-Aquitaine*)

Société de neuropsychologie de langue française (SNLF) [French Language Society of Neuropsychology]*

Société française d'anesthésie-réanimation (SFAR) [French Society of Anaesthesia and Intensive Care]

Société française d'oto-rhino-laryngologie (SFORL) [French ENT Society]

Société française de neurologie pédiatrique (SFNP) [French Society of Paediatric Neurology]*

Société française de pédiatrie (SFP) [French Society of Paediatrics]*

Société française de physiothérapie (SFP) [French Society of Physiotherapy]

Société française de radiologie (SFR) [French Society of Radiology]

Société française de santé publique (SFSP) [French Society of Public Health]*

Union nationale des associations de parents et amis de personnes handicapées mentales (UNAPEI) [National Union of Associations of Parents and Friends of the Mentally Disabled]*

Union nationale pour le développement de la recherche et de l'évaluation en orthophonie (UNADREO) [National Union for the Development of Research and Assessment in Speech Therapy]*

(*)This stakeholder provided an official opinion

Translation

RWS Language Solutions

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Information sheet

Title	Autism spectrum disorders - Warning signs, detection, diagnosis and assessment in children and adolescents
Work method	Clinical practice guidelines (CPG)
Objective(s)	<ul style="list-style-type: none"> • to optimise the detection of children with signs of ASD or unusual development or at risk of developing an autism spectrum disorder (younger) • to harmonise the practices and procedures for diagnosis of an ASD in children or adolescents
Patients or users concerned	<ul style="list-style-type: none"> • Any child or adolescent, under 18 years of age, with signs of ASD or unusual development or at risk of developing an autism spectrum disorder • His/her parents
Professionals concerned	The professionals involved in the detection and diagnosis of ASD in children and adolescents are numerous and are involved in part or all of the pathway from detection to diagnosis: early childhood or school/national education professionals, general practitioners, paediatricians and paediatric psychiatrists and other specialists, psychologists, specialised educators
Requesting party	Marisol Touraine, Minister of Social Affairs, Health and Women's Rights, and Ségolène Neuville, Secretary of State for the Disabled and the Fight against Exclusion (2016)
Sponsor	Haute Autorité de santé (HAS), Department for Good Professional Practices
Financing	Public funds
Project steering	Coordination: Dr Muriel Dhénain and Ms Joëlle André-Vert, project managers, HAS Department for Good Professional Practices (head of department: Dr Michel Laurence) Secretary: Ms Laetitia Gourbail
Document search	From January 2005 to November 2016 (see literature search method described in Appendix 2 of the evidence report); a current awareness was carried out until November 2017. Performed by Mr Philippe Canet, with assistance from Ms Renée Cardoso (head of documentation department – watch: Ms Frédérique Pagès)
Authors of the evidence report	Ms Nathalie Marpillat, pharmaco-epidemiologist; Mr René Pry, university professor, psychologist; Ms Joëlle André-Vert, project manager, HAS; Dr Muriel Dhénain, project manager, HAS
Participants	Professional bodies and associations of patients and users, working group (co-chairs: Prof. Amaria Baghdadli, child and adolescent psychiatrist, Montpellier, and Dr Isabelle de Beco, general practitioner, Paris), reading group and other people consulted: see list of participants
Conflicts of interest	Members of the working group have sent their public interest declarations to HAS; these can be seen on www.has-sante.fr or https://dpi.sante.gouv.fr/ . They were analysed according to the analysis grid in the HAS guide on the declaration of interests and management of conflicts of interest. The interests declared by the working group members were considered as being compatible with their participation in this work.
Validation	This document was adopted by the HAS Board in February 2018.
Updating	Updating of the guideline will be considered depending on the data published in the scientific literature or significant practice modifications occurring since publication.
Other formats	The evidence report and summary of the best practice guideline can be downloaded from www.has-sante.fr

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