

Clinical Practice Guideline for the Management of Childhood Autism Spectrum Disorder in Primary Care. Update

Short version

**Clinical Practice Guidelines in the Spanish NHS
Ministry of Health**



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1. Introduction

This CPG addresses the definition and classification of autism spectrum disorder (ASD) in DSM-5, diagnostic criteria and early detection, ASD suspicion management and strategies for monitoring in primary care. Additionally, it addresses the values and preferences of patients and their family.

This guide focuses on children from 0 to 6 years old, a period that covers most of the diagnoses of ASDs and which coincides with the Early Warning Surveillance period. This timeframe excludes adolescents and adults.

This guideline updates the recommendations of the CPG for the Management of patients with autism Spectrum Disorders in Primary Care, published in 2009.

This version in English contains the following types of information:

- **Clinical questions**
- **Recommendations**
- **Rationale**
- **Complete clinical question** (link to the version in Spanish)
- **References**

To access the full version of the CPG (as a multilayer presentation or PDF), the methods employed, material for patients, families and other caregivers, and other information in Spanish please click on the following link:

<https://portal.guiasalud.es/gpc/trastorno-espectro-autista-infancia-atencion-primaria/>

2. Definition and classifications

Questions

- *What is the definition of ASD in the DSM-5-TR and what clinical manifestations do they include?*
- *What is the classification of ASD in the DSM-5-TR?*

Definition of ASD

ASD is a developmental disorder defined to a spectrum in the DSM-5, because of variability in the severity of clinical manifestations, level of cognitive ability and chronological age. ASD includes several previous subtypes defined in DSM-IV (autistic disorder, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified).

The essential characteristics of ASD are grouped in two criteria, based on Wing triad:

- A. A persistent impairment in social communication and social interaction.
- B. A restricted and repetitive patterns of behaviour, interests or activities.

Complete clinical question

For full information on this question (available in Spanish), see:
https://portal.guiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-1

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3. Diagnostic criteria

Questions

- *In children under 6 years, what criteria must be fulfilled to classify in ASD category of DSM-5-TR?*
- *In children under 6 years, are the diagnostic criteria laid down in the DSM-5-TR or ICD-11 manuals useful for ASD diagnostic?*

Recommendations

The following recommendation was retired:

1. It is recommended that professionals involved in the detection of children with ASD, especially those with little experience, use the diagnostic DSM-IV-TR and /or ICD-10 manuals

Rationale

Below, we outline the rationale for one of the recommendations, highlighting the judgements of the GDG concerning the key criteria that justify the final recommendation.

The recommendation on diagnostic criteria according to the classification of DSM-IV-TR and ICD-10 was considered invalided, and not applicable to current clinical practice. No evidence was identified comparing the diagnostic criteria from recently updated manuals with previous versions to update the recommendation. Low quality and heterogeneous evidence were identified in the selected guidelines. No systematic reviews and primary studies were retrieved. Therefore, a new recommendation was not endorsed due to a lack of evidence.

Complete clinical question

For full information on this question (available in Spanish), see:

https://portal.guiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-2

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4. Early detection

Follow-up of a healthy child for early detection of ASD

Question

- *How should the monitoring of a healthy child in Primary Care be to detect problems early in his or her development?*

Recommendations

2. Health and educational professionals should regularly discuss with parents the psychomotor, intellectual and behavioural development of their children (at least between 8-12 months, between 2-3 years and between 4-5 years old) as part of the monitoring of the healthy child (D, valid)
3. Health professionals should incorporate a high level of vigilance in the fields of social, play, language and behaviour development for the early identification of ASD and related disorders (D. valid)
4. In the monitoring of healthy child development in Primary Care, to help detect any developmental disorder, including ASD, it is recommended the use of scales (such as the Haizea Llevant scale developed in our context) (✓, valid)

Rationale

Below, we outline the rationale for one of the recommendations, highlighting the judgements of the GDG concerning the key criteria that justify the final recommendation.

The development group agreed to consider three valid recommendations from the Clinical Practice Guideline for the Management of Patients with Autism Spectrum Disorders in Primary Care on follow-up of healthy child. These recommendations are related to the importance of valuing by healthcare and educational professionals, as well as by the families/carers, the psychomotor, intellectual, and behavioural development in the children at different stages, the follow-up in the field of social, play, language and behaviour development, alongside daily life activities. Furthermore, the development group agreed to use the Haizea-Llevant scale to monitor the development within the healthy child program in primary care.

Complete clinical question

For full information on this question (available in Spanish), see:

https://portal.quiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-3

References

Grupo de Trabajo de la Guía de Práctica Clínica para el Manejo de Pacientes con Trastornos del Espectro Autista en Atención Primaria. Guía de Práctica Clínica para el Manejo de Pacientes con Trastornos del Espectro Autista en Atención Primaria. 2009. URL: https://portal.guiasalud.es/wp-content/uploads/2018/12/GPC_462_Autismo_Lain_Enr_compl.pdf

Warning Signs and Scales

Question

- *Are there any useful warning signals / criteria for specific suspicion of ASD for early detection in Primary Care?*

Recommendations

1. Healthcare professionals should monitor the development of healthy children taking into account the “warning signs” proposed:
 - Immediate warning signals
 - Compendium of ASD warning signs according to age periods (D, √, valid)
2. When considering the possibility of autism, be aware that (weak, adopted):
 - Signs and symptoms should be seen in the context of the child’s or young person’s overall development
 - Signs and symptoms will not always have been recognised by parents, carers, children or young people themselves or by other professionals
 - When older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person’s coping mechanisms and/or a supportive environment
 - It is necessary to take account of cultural variation, but do not assume that language delay is accounted for because Spanish is not the family’s first language or by early hearing difficulties
 - Autism may be missed in children or young people with an intellectual disability
 - Autism may be missed in children or young people who are verbally able
 - Autism may be under-diagnosed in girls
 - Important information about early development may not be readily available for some children and young people, for example looked-after children and those in the criminal justice system
 - Signs and symptoms may not be accounted for by disruptive home experiences or parental or carer mental or physical illness.

Rationale

Below, we outline the rationale for one of the recommendations, highlighting the judgements of the GDG concerning the key criteria that justify the final recommendation.

One recommendation favourable to follow-up of children take account warning signs of development disorders was considered valid.

One recommendation was adopted of the NICE Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum. The recommendation was favourable to the signs and symptoms analysis of suspected ASD in the context of the child's or young person's overall development, take account the cultural and gender variation, and intellectual and verbal ability, as well as the possibility of the unrecognized or be masked by the child or young person's coping mechanism in a supportive environment. The GDG considered the favourable benefit-harm balance, the importance to the patients and their families/carers, and the assessment would not suppose a relevant additional cost with respect to routine clinical practice.

Complete clinical question

For full information on this question (available in Spanish), see:

https://portal.guiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-3

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Early screening scales

Question

- *What rating scales of suspected ASD are most effective?*

Recommendations

1. Population screening for ASDs is not recommended with the instruments developed at this moment, although the capability of the M-CHAT and the Autonomous Scale is being investigated (C, valid)

2. Be aware that tools to identify children and young people with an increased likelihood of autism may be useful in gathering information about signs and symptoms of autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism (weak, adopted).

Also be aware that:

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

Rationale

Below, we outline the rationale for one of the recommendations, highlighting the judgements of the GDG concerning the key criteria that justify the final recommendation.

One recommendation against the population screening for ASD with the instruments developed at this moment was considered valid.

One recommendation was adopted of the NICE Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum CG128, indicating that the tools to identify children and young people with an increased likelihood of autism may be useful in gathering information about signs and symptoms of autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism, highlighting that a positive or negative result might not correspond in all cases to a diagnosis of ASD or the absence of this disease, respectively.

The balance of desirable and undesirable consequences was considered favourable to use tools or scales in gathering information in a structured way to assess the suspected ASD; however, the GDG considered an unfavourable balance to use these tools to make or rule out a diagnosis of autism.

The GDG considered that most patients, once informed of the pros and cons, would agree with the recommendation adopted.

Most of the tools available for identifying signs or symptoms of autism in routine clinical practice could be used in a clinical assessment without significant costs.

Complete clinical question

For full information on this question (available in Spanish), see:

https://portal.guiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-3

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Minimum age of suspicion

Questions

- *What is the minimum age in that is possible to detect warning signs or alarm signals indicating a possible ASD?*

Complementary question:

- *What age should be ASD included in the differential diagnosis of neurodevelopmental disorders?*

Recommendations

1. Practitioners should monitor the presence of any warning signals from at least 6 months of age (C, valid)
2. Given that there is no evidence of a minimum age for alterations, referral to Specialised Care may be considered at any age when there is a suspicion of ASD (✓, valid)
3. ASD should be included in the differential diagnosis in children of any age in whom warning signs or symptoms of neurodevelopmental disorder are detected. (Good practice statement, de novo)

Rationale

Below, we outline the rationale for one of the recommendations, highlighting the judgements of the GDG concerning the key criteria that justify the final recommendation.

The recommendations on vigilance of warning signs from at least 6 months of age, and to refer to specialised care at any age when there is a suspicion of ASD were considered valid.

No evidence of quality was identified in the systematic review carried out on the minimal age to detect signs or symptoms of a suspicion of ASD, and no evidence was identified to update the recommendation of the 2009 CPG on the vigilance age appropriate for warning signs of ASD.

The GDG unanimously approved one good practice declaration based on the judgments on the included criteria in the evidence to decision framework, and indirect evidence.

Complete clinical question

For full information on this question (available in Spanish), see:

https://portal.quiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-3

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5. ASD suspicion management strategies in Primary Care

Question

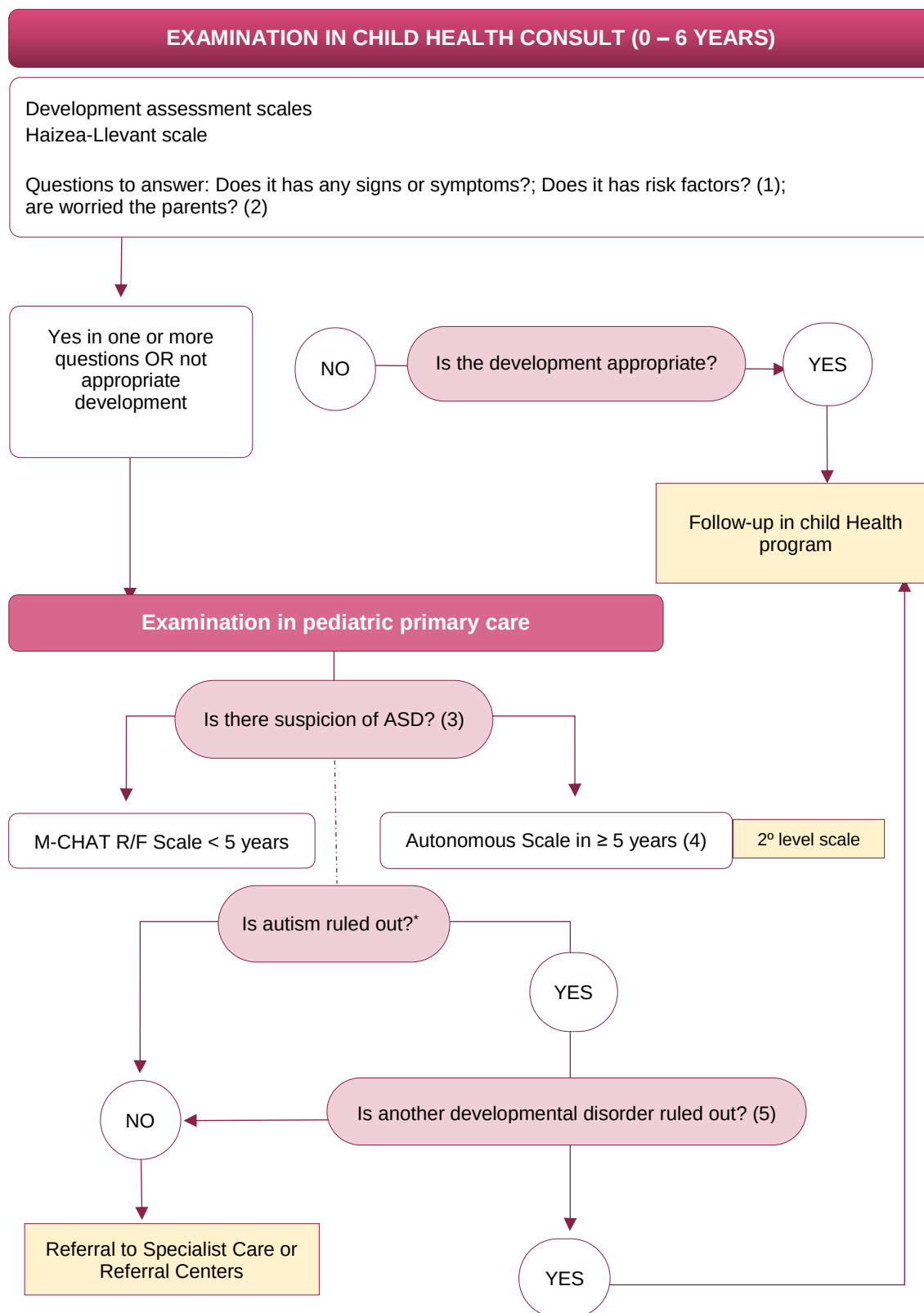
- *What are the steps to follow if there is any suspicion of ASD?*
- *What are the referral criteria of ASD?- Algorithm*

Steps to be taken if there is a suspicion of ASD

As initial guidance, in a patient with symptoms of ASD, the following algorithm is presented as an update to the 2009 guide, to guide the referral work, based on the recommendations made earlier in the guide:

Neurodevelopmental assessment to ASD detection in Primary Care

ALGORITHM FOR THE MANAGEMENT OF SUSPECTED ASD IN PRIMARY CARE



* Clinic judgement based on global Evaluation in pediatric primary care

Notes on the management algorithm of ASD suspicion in Primary Care

- (1) ASD Risk factors to be considered when assessing the child's background: perinatal factors (consumption of drugs or teratogenic substances, perinatal infections, gestational diabetes, gestational bleeding, foetal distress, prematurity, low birth weight), metabolic diseases, older parents, parents with a history of psychosis or affective schizophrenia and family history (siblings with ASD).

The GDG agrees to risk factors considered to NICE guideline CG128, based on low quality of evidence (clinical threshold OR/RR > 1.25):

- Sibling history of ASD
- Parental history of schizophrenia-like psychosis.
- Paternal or maternal age over 40 years
- Birthweight less than 2500 gr
- Prematurity under 35 weeks
- Admission to a neonatal intensive care unit
- Any or multiple birth defects
- Male gender
- Threatened abortion at before 20 weeks

On reference to risk factors, the GDG considered relevant the lack of information on parental history in children adopted internationally, as well as the lack of information on risk factors in gamete/embryo donors for in vitro fertilization procedures.

- (2) The concern of parents. Parent's Evaluation of Development Status Scale (PEDS). To guide the professional about what to ask parents.
- (3) Discard metabolic and hearing disorders
- (4) M-CHAT-R/F and Autonomous Scale. Use as a supplement if there is a suspicion in children:
 - Under 5 years: M-CHAT-R/F (Self-administered to parents)
 - Over 5 years: Autonomous Scale (Self-administered to parents and teachers)
- (5) Other developmental disorders. It refers to the presence of other disorders that do not meet the criteria of ASD, such as motor skills disorders (for example ataxia, poor coordination, hypotonia that are indicative of Infantile Cerebral Palsy, etc.) intellectual disability (any grade), learning disorders, or communication disorders (expressive, receptive, mixed or phonological) and others.

6. Strategies for monitoring children with ASD in Primary Care

Questions

- *How to plan the visit of children with ASD in Primary Care?*
- *What issues should be explored / monitored in the Primary Care visit of children with ASD?*

Recommendations

1. Professionals should take account of the symptoms and behavioural disorders of children with ASD to prepare, in coordination with parents, the visits of the child to prevent overstimulation and confusion or potential health problems or risk behaviours (✓, valid)
2. It would be useful to register children with ASD by maturation level (IQ or developmental level) as it is a key prognostic factor, which determines the global evolution (learning, communication, social skills) (C, valid)
3. Professionals can use visual support interventions such as the use of pictograms, cartoons, dolls imitation, to support communication processes in children with ASD. Example: to show them the instruments, procedures and techniques, exploration of pain and other symptoms (B, valid)
4. Professionals should use short simple sentences, without double meanings to communicate previously to the child what he or she will do, and use direct orders when asking them for something, using the support of parents to understand and communicate (D, valid)
5. In the visit of children with ASD, Primary Care professionals should (✓, valid):
 - Coordinate with the parents so that they anticipate the visit to the child
 - Try not to wait for a long time in the waiting room, especially if it is full of other patients
 - Trust in the management criteria of parents
 - Welcome the child in a calm and orderly environment
 - Reinforcements with prizes (toys, stickers and others) may facilitate future visits
 - In case a certain procedure that involves physical contact is required, it is necessary to assess risk/ benefit of doing so. For example, a blood test, for which the child should be as much prepared as possible, accepting more flexible rules such as allowing the parent to accompany the child or adapting the procedure if necessary
 - Be aware of disorders and behavioural sensitivity to detect masked symptoms such as pain, certain harmful or dangerous habits like inhaling or ingesting toxic substances, self-harm
 - Adjust the format of the medication to the child's preferences as much as possible (i.e. syrups instead of tablets)

6. Professionals should monitor nutritional status of children with ASD, recommending dietary supplements if necessary or even referring (D, valid)
7. Professionals should manage the gastrointestinal problems of children with ASD in the same way as those of children without ASD, taking into account that the existence of functional gastrointestinal problems (constipation, bowel disorders, and others) can have major adaptive and behavioural consequences than in population without ASD (D, valid)
8. Professionals should inform parents about healthy habits such as diet or exercise, leisure and free time activities, selecting those that, within the limits of the family and those provided by the community, provide enjoyment and child welfare (✓, valid).
9. Monitor oral health of children with ASD. In case of eating toothpaste, do recommend one without fluoride. Patients and parents' associations and parents can provide guidance on which dentists have experience attending children with autism, as sometimes certain changes in the procedures may be necessary. The same applies if ophthalmic check-ups are required (D, valid)
10. All children with ASD should follow the immunisation schedule established just like any other children, including vaccination of MMR (rubella, measles and mumps). Professionals should inform about the importance of this to parents (B, valid)
11. Professionals should monitor the presence of sleep disorders, using as a first step behavioural strategies to manage them and training parents on this issue (C, valid)
12. Professionals should inform parents that there is no evidence that ASDs are associated with digestive disorders (C, valid)
13. Professionals should inform parents that currently there is no evidence of the effectiveness of diets free of gluten and casein, secretin, vitamin B6 plus magnesium, Omega-3 fatty acid, dimethylglycine, and hyperbaric oxygen therapy for specific treatment of ASD (A,B, reviewed and modified)
14. Professionals should inform parents that currently there is no evidence of the effectiveness of antifungal therapy, chelating agents and immunotherapy (C,D, valid)
15. Professionals should inform parents that there are currently some "alternative treatments" that have no scientific basis to support their use and could be potentially dangerous, so they should be advised to consider only of those interventions recommended by professionals (✓, valid)

Rationale

Below, we outline the rationale for one of the recommendations, highlighting the judgements of the GDG concerning the key criteria that justify the final recommendation.

No systematic reviews and no primary studies were found to update the recommendations related to question 10. The GDG considered valid 10 recommendations and 4 GPS favourable to the professionals take account the symptoms and behavioural disorders of children with ASD

to prepare, in coordination with parents, the visits of the child, and to register children with ASD by maturation level.

The GDG was favourable to use of visual support interventions, short simple sentences, without double meanings to communicate previously to the child what he or she will do, and use direct orders when asking them for something, using the support of parents to understand and communicate. The GDG was favourable to coordinate with the parents so that they anticipate the visit to the child, to the attention of sensitivity and behaviour disorders to detect masked symptoms, adjust the format of the medication to the child's preferences as much as possible, monitor nutritional status of children, manage the gastrointestinal problems in the same way as those of children without ASD, as well as inform parents about healthy habits, monitor oral health and follow the immunisation schedule established just like any other children including vaccination of MMR (rubella, measles and mumps).

The GDG was favourable to monitor the presence of sleep disorders, and inform to parents that currently there is no evidence of ASD with digestive disorders, and no evidence of the effectiveness of diets free of gluten and casein, secretin, vitamin B6 plus magnesium, Omega-3 fatty acid, dimethylglycine, and hyperbaric oxygen therapy, antifungal therapy, chelating agents and immunotherapy.

The GDG considered it necessary to inform parents that there are currently some "alternative treatments" that have no scientific basis to support their use and could be potentially dangerous.

Complete clinical question

For full information on this question (available in Spanish), see:

https://portal.guiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-4

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7. Perspective of the ASD people and their family setting

The evidence search regarding values and preferences for people with ASD identified two documents that met the selection criteria.

One systematic review analyzed the qualitative Evidence related to the parents' experiences of their children's ASD diagnosis in the United Kingdom.

The U.S. Food and Drug Administration (FDA) published one report in 2018 based on the perspectives of people with autism, family, caregivers, and other patient representatives, related to significant health effects and the impact on daily life, as well as currently available therapies for autism.

Complete chapter

For full information on this chapter (available in Spanish), see:

https://portal.guiasalud.es/guia-en-capas/gpc_652_tea_actualizacion/#question-5

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