FAQ — 100 Questions About Autism

A parents’ guide, question by question

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FREE GUIDE

Introduction — How to use this FAQ

This FAQ was written for you: a parent who has just received a diagnosis, a grandparent who feels lost, a teacher discovering a different child in the classroom, a soon-to-be-diagnosed adult trying to understand themselves, or simply someone curious about the subject. You will find 100 concrete questions and 100 clear answers, grouped into 10 broad categories that follow the real journey of a family touched by autism.

How should you use it? Three options. You can read it in order, from the first question to the hundredth: in a few hours you will have an overview of the whole subject. You can also jump straight to the category that concerns you today — diagnosis, schooling, paperwork — and come back to the rest later. Finally, you can use it as a mini-dictionary, searching for a specific word (autism, sensory, PECS, ABA) in the table of contents.

Important: this FAQ is a starting point, not a substitute for medical advice. With every question, we remind you to consult a professional for any decision about your child's health. The sources cited (international health agencies, research institutes, the CDC, the WHO, autism organizations) are verifiable and up to date with 2023–2025 recommendations. No method is presented as a "miracle": we give the official positions, the available scientific evidence, and we steer clear of simplistic promises.

You will also find, here and there, short personal reflections from Valentine, mother of an autistic child and author of the book *Breaking the Codes*. These passages are not medical advice but glimpses of lived experience — because a parent talking to a parent is often what helps the most.

This FAQ is a living document. If you cannot find your question among these 100, write to us via sortirdelautisme.fr — we will add it in a future edition. Enjoy your reading, and above all: do not stay alone.

> One thing to remember before you begin: No question is silly. None goes too far. No expert term should intimidate you — behind every acronym there is a concrete reality that this FAQ will explain.

Category 1 — Understanding autism

Ten questions to set the foundations: what autism is, where it comes from, how to distinguish it from other situations, and what has genuinely changed over the past twenty years.

Q1. What exactly is autism?

Autism — or more precisely Autism Spectrum Disorder (ASD) — is a neurodevelopmental condition that appears in early childhood and lasts a lifetime. It is characterized by two broad categories of features according to the DSM-5: difficulties in communication and social interaction (delayed or absent language, limited eye contact, difficulty understanding social codes), and restricted, repetitive behaviors, interests or activities (stereotyped movements, rigid routines, specific interests, sensory particularities). We speak of a "spectrum" because the expression of these features varies enormously from one person to another: one child may be non-verbal and need constant support, while another may speak fluently and go almost unnoticed in society. Autism is not a mental illness, it is not an intellectual disability (even though the two can coexist), and it is in no way the consequence of poor parenting. It is a different way the brain works, present from birth, which gradually reveals itself between 12 and 36 months in most children concerned. Always consult a professional for any medical doubt.

Sources: international clinical guidelines on ASD; DSM-5 (APA, 2013); research-institute autism dossiers, updated 2023.

Q2. How many people are autistic worldwide?

According to leading estimates, about 1 person in 100 is affected by an autism spectrum disorder. The WHO likewise uses a figure of roughly 1% of the population. In the United States, the CDC publishes higher figures: their 2023 ADDM survey shows that 1 child in 36 is diagnosed autistic at age 8, that is nearly 2.8%. This difference does not mean there is "more autism" in America: it mainly reflects broader screening criteria, better professional training, and earlier detection. Girls are widely thought to be under-diagnosed: the observed sex ratio is 3 to 4 boys for 1 girl, but recent studies suggest a real ratio closer to 2 to 1, or even 1.5 to 1. For up-to-date data, consult your national autism association.

Sources: international clinical guidelines; research-institute data 2023; CDC ADDM 2023; WHO Fact Sheet 2023.

Q3. Is autism an illness that can be cured?

No, autism is not an illness you catch and then cure. It is a neurological way of functioning present from birth, which will accompany the person all their life. That does not mean there is nothing to do — quite the opposite. With early detection and appropriate support (speech therapy, psychomotor therapy, structured behavioral interventions, educational support, sometimes treatment for associated difficulties such as anxiety or sleep), a great many children make considerable progress: they acquire language, autonomy, social relationships, sometimes to the point where their symptoms diminish significantly (this is called an "optimal trajectory"). But be wary of claims promising a “miracle cure” through some diet, plant, or alternative therapy: no method of that kind has scientifically proven its effectiveness, and some are even dangerous (chelation, MMS, etc., formally advised against by health authorities and medicines agencies). The realistic and achievable goal is the flourishing, autonomy and quality of life of the autistic person, not the erasure of autism. Always consult a professional.

Sources: international clinical guidelines; medicines-agency MMS alerts; collective scientific reviews.

Q4. What causes autism?

Current research converges on a multifactorial origin, mainly genetic. More than 200 genes have been identified as associated with an increased risk of autism, and heritability is estimated at between 60% and 90% according to twin studies (Tick et al., 2016). This does not mean that autism is “hereditary” in the classic sense: it often involves complex combinations of genetic variations, sometimes spontaneous (de novo) mutations that appear at the moment of conception. To these genetic factors are added environmental factors that can modulate the risk: advanced parental age, significant prematurity, prenatal exposure to certain medications (notably valproate), obstetric complications. Note: no serious study has demonstrated a link between vaccination and autism. The Wakefield study (1998) that suggested such a link was fraudulent, retracted, and its author struck off. Meta-analyses covering more than a million children (Taylor 2014; Jain JAMA 2015; Hviid Annals 2019) are unequivocal: no causal link. Vaccinations protect autistic children just as they protect others.

Sources: research-institute data 2023; Tick et al. 2016; Hviid et al. Ann Intern Med 2019; WHO 2023.

Q5. What is the difference between autism, Asperger and ASD?

Until 2013, several sub-categories were distinguished within the “family” of pervasive developmental disorders: typical Kanner autism, Asperger syndrome (autism without language delay or intellectual disability), childhood disintegrative disorder, and PDD not otherwise specified. Since the DSM-5 (2013) and the ICD-11 (2019), all these diagnoses have been grouped under a single term: Autism Spectrum Disorder (ASD). Today we speak of ASD with or without associated intellectual impairment, with or without language impairment, and we specify the level of support needed (level 1: requires support; level 2: requires substantial support; level 3: requires very substantial support). The term “Asperger” is still used in popular culture and within the communities concerned, but it no longer appears in official diagnoses. Many adults diagnosed before 2013 nonetheless continue to identify as “Aspies,” and that is perfectly fine: it is above all a matter of personal identity.

Sources: DSM-5 (APA 2013); ICD-11 (WHO 2019); international clinical guidelines.

Q6. Is autism on the increase?

Statistically, yes, but the reading is nuanced. In the 1980s, prevalence was estimated at 4 cases per 10,000 children (0.04%). Today it is about 25 times higher. This apparent “explosion” is explained for the most part by: 1) the broadening of diagnostic criteria (the inclusion of Asperger in 1994, the ASD grouping in 2013); 2) far better training of health and early-childhood professionals; 3) increasingly early detection (around 18–24 months today versus 5–6 years twenty years ago); 4) the recognition of girls and of more subtle presentations. There remains a residual portion of "true" increase that researchers are actively studying: parental age, prematurity, perinatal environment. But no serious study suggests an "epidemic" or a single cause. The current scientific consensus is that we are better at diagnosing what was previously invisible, rather than suddenly producing autistic children.

Sources: CDC ADDM 2023; research-institute data 2023; Lyall et al., Annu Rev Public Health 2017.

Q7. What does "neurodevelopmental disorder" mean?

The term "neurodevelopmental disorder" (NDD) refers to a large family of conditions that appear during the brain's developmental phase — that is, before or during pregnancy, at birth, or in the first years of life. This family includes: autism spectrum disorder (ASD), attention deficit disorder with or without hyperactivity (ADHD), specific learning disorders (dyslexia, dyscalculia, dysorthographia, dysgraphia), language disorders, dyspraxia, and intellectual disability. These conditions have in common that they affect brain maturation, are present from early childhood, last a lifetime, and frequently coexist with one another (this is called comorbidity). Understanding that an autistic child sometimes also has ADHD, dyspraxia or sleep disorders is therefore not an exception: it is rather the rule.

Sources: NDD care pathways; research-institute data 2023; national autism strategies.

Q8. Can someone be autistic without knowing it?

Yes, and it is in fact very common. Many adults — especially women — discover their autism at 30, 40, 50 years old, sometimes when one of their own children is diagnosed. For decades, autism was thought of as a male, severe, visible disorder. So a whole part of the population was missed: intellectually bright but socially awkward children, women who "mask" their difficulties by imitating others, people labeled "shy," "odd," "eccentric," "rigid." With the broadening of criteria and the media attention given to so-called "mild" autism, late diagnoses are multiplying. A diagnosis in adulthood is far from pointless: it puts a word to decades of incomprehension, allows access to disability-related support and employment recognition where it exists, and above all helps people understand themselves better. Your national autism association can guide you toward a team specialized in adult diagnosis. Expect waiting times of 12 to 24 months on average in public services.

Sources: international clinical guidelines on adult ASD; national autism resource networks 2023; Lai and Baron-Cohen, Lancet 2015.

Q9. Are autism and intellectual disability the same thing?

No, they are two quite distinct things, even though they can coexist. Intellectual disability is defined by an IQ below 70 and significant difficulties adapting to everyday life. Autism, by contrast, is a disorder of social functioning and communication, independent of intellectual level. One can be autistic with a very high IQ (the so-called "high-functioning" autistics or former Asperger profiles); one can be autistic with an average IQ and go unnoticed for years; one can be autistic with an associated intellectual disability, which complicates the picture and requires reinforced support. About 30% of autistic people also have an intellectual disability (2023 estimate, steadily decreasing as detection among verbal children improves). It is important to measure IQ in a setting adapted to autism (WISC-V or Leiter test for children with little speech), because a poor result may reflect sensory or attentional difficulties rather than a true disability.

Sources: DSM-5; research-institute data 2023; diagnostic-assessment guidelines.

Q10. What is neurodiversity?

The word "neurodiversity" was coined in 1998 by the Australian sociologist Judy Singer, herself autistic. It refers to the idea that variations in brain functioning (autism, ADHD, dyslexia, Tourette syndrome) are natural forms of human diversity, just like gender, cultural or linguistic diversity. The neurodiversity movement argues that neuroatypical people do not have a "broken" brain to be repaired, but a different brain that deserves to be accepted, supported and included. This view has profoundly changed the way autism is seen over the past twenty years: there is less talk of "curing" and more of "supporting" and "adapting the environment." That said, the concept of neurodiversity is not universally embraced by families, and that is legitimate: for a parent whose child is non-verbal, has self-injurious crises, or cannot live alone, talking about a "simple difference" can feel very far from daily reality. The two approaches — neurodiversity and intensive care — are not opposed: they respond to different situations within the spectrum.

Sources: Singer J. 1998; Ortega F., BioSocieties 2009.

> Valentine's reflection: "When my son was diagnosed, I wanted to understand everything in one night. What really helped me was realizing that autism is not a wall, it's a landscape. With ten different ways in."

Category 2 — Recognizing the signs by age

Ten questions to help you identify, at each age range, the signs that should catch your attention. Important: a single sign is not enough, and every child has their own pace. It is the accumulation of several signals that should lead you to seek advice.

Q11. What are the warning signs of autism between 0 and 6 months?

At this age, the signs are subtle and hard to spot, even for professionals. We tend to look for the absence of expected behaviors rather than the presence of abnormal ones. Things that should catch your attention: a baby who does not look at their parents' eyes during feeding, who does not smile back around 2–3 months (the social smile), who does not react to the human voice or to loud noises (check hearing first), who seems "too calm" or, conversely, constantly irritable, who does not settle when held (a stiff or completely limp body), who does not follow objects with their eyes at 4 months. Note: none of these signs taken alone means autism. Many very calm babies are simply good sleepers; many irritable babies are teething. It is their persistent combination that should lead to medical advice. Developmental screening at around 9 months and 24 months is now widely recommended. Never hesitate to share your observations with your pediatrician.

Sources: child-health screening recommendations; CDC Learn the Signs Act Early 2023.

Q12. What are the signs between 6 and 12 months?

Around 6–9 months, a typical baby begins to actively explore the social world. Signs to watch for include: no babbling ("bababa," "mamama") at 9 months, no proto-declarative pointing (the child does not point at an object to share it with you), no response to their name at 10–12 months (a very telling sign, after a hearing check), no imitation of facial expressions or simple gestures (peekaboo, waving goodbye), no reaching up to be picked up, an avoidant or indifferent gaze when spoken to, a preferential interest in objects rather than faces. A lack of joint attention — the ability to share visual focus with an adult around an object or event — is one of the most specific early signs. If at 12 months your child does not point, does not show, does not hand an object over to share it, talk to your doctor. The M-CHAT-R, usable from 16–18 months, is a validated screening tool that many pediatricians now use.

Sources: Robins et al., M-CHAT-R 2014; international clinical guidelines; AAP Bright Futures 2023.

Q13. What signs around 12–18 months?

It is between 12 and 24 months that autism begins to become more visible. Red flags at 12–18 months: no first words at 15–16 months, no pointing at 12 months, no joint attention, no imitative play (pretending to feed a soft toy), gaze withdrawal, obvious social disinterest, no response when their name is called several times, unusual fascination with spinning objects (wheels, fans, washing machines), lining up objects, repetitive gestures (hand-flapping, rocking), unusual sensory reactions (covering the ears at harmless noises, or conversely not reacting to a loud noise), early feeding difficulties (refusing textures, eating only one color). If you notice several of these signs, know that in many countries you can access early assessment and intervention without waiting for a formal diagnosis — ask your primary care doctor or your national autism association.

Sources: NDD care pathways; early-intervention services; CDC Milestones 2022.

Q14. And between 18 and 24 months?

This age range is crucial: detection at this point allows early intervention whose benefits are documented (Dawson et al., Pediatrics 2010 on the ESDM). Warning signs at 18–24 months: fewer than 5–10 words at 18 months, no two-word combinations at 24 months (“daddy gone,” “more milk”), regression of language or of contact (loss of words, loss of eye contact, loss of previously present smiles — this is a major red flag), absence of symbolic play (no pretending), ritualized behaviors (melting down if a route is changed, not tolerating their objects being touched), unusual interests (can spend 30 minutes spinning a car wheel), absence of proto-declarative pointing, lack of social reciprocity, marked sensory particularities. Where a doubt exists, the M-CHAT-R/F should be offered systematically. Your primary care doctor can then refer you toward early-assessment services. These services fund and organize the first assessments (psychomotor, speech, psychological) even before the diagnosis.

Sources: international clinical guidelines; Dawson et al., Pediatrics 2010; early-intervention services.

Q15. What are the signs in a 2–3 year old child?

Between 2 and 3 years, the gaps with typical development become clearer. Suggestive signs: marked language delay (fewer than 20 words at 2 years, no short sentences at 3 years) or atypical language (echolalia, repeating phrases heard on television, a monotone voice, very formal or robotic speech), major difficulties relating to peers (the child plays alongside but not with others, or avoids them altogether), absence of pretend play, intense restricted interests (always the same cartoons, the same objects; can name 50 dinosaurs but not say hello), rigid routines, massive meltdowns at change, walking on tiptoe, stereotyped gestures (flapping, rocking), very marked sensory particularities (seeking strong sensations, or extreme avoidance of noise, touch, food textures). At this age, you should seek advice without delay. A local diagnostic team or specialist autism service can confirm or rule it out. Do not wait for the start of preschool to act: every month counts.

Sources: international clinical guidelines; DSM-5; CDC Milestones 2022.

Q16. How does autism present around 3–6 years?

This is typically the age at which the diagnosis is made (around 4–5 years on average — still too late, since the target is age 3). At this age, the autistic child can present in very different forms. Some are minimally verbal or non-verbal, and use little or no language to communicate their needs; others speak very well, but in an out-of-step way (monologues on their favorite subjects, difficulty holding a dialogue, taking turns, understanding the implicit, humor, irony). We often observe: major difficulties joining in collective play, rigidity around change (the start of the school year, a new sweater, a new teacher become ordeals), very intense specific interests (dinosaurs, trains, planets, numbers), sensory particularities (refusing clothes with labels, panicking at hand dryers, an intense visual interest in lights), sleep and feeding disorders, sometimes challenging behaviors (self-injury, running off, meltdowns). This is the age when schooling begins to reveal — or worsen — the difficulties. Structured support is essential.

Sources: international clinical guidelines; research-institute data 2023; national autism strategies.

Q17. Can autism appear after age 6?

No, autism does not “start” after age 6. It is a neurodevelopmental condition present from birth. However, it may be diagnosed late, especially in children who have compensated for their difficulties or whose signs were subtle. This is particularly true for: girls, who often learn to “mask” socially; children with preserved IQ, whose particularities are put down to personality (“he’s just shy,” “she’s mature for her age”); children whose associated difficulties (ADHD, anxiety, learning disorders) absorbed all the attention. Starting primary school, then secondary school, can reveal previously invisible difficulties: sensory overload, massive anxiety, school refusal, bullying, social phobia, eating disorders. If a diagnosis is made at 8, 10, 14 years old, it is never “too late”: putting accommodations in place, arranging specialized follow-up, and the child’s understanding of themselves profoundly change the trajectory. Many adolescents diagnosed late describe an immense sense of relief.

Sources: Lai and Baron-Cohen, Lancet 2015; international clinical guidelines; autism resource networks 2023.

Q18. Why are girls diagnosed later?

Autistic girls remain largely under-diagnosed and are, on average, identified 6 years later than boys. Several reasons: 1) diagnostic criteria were historically built from observations of boys, and do not always capture the female presentation; 2) girls tend to “mask” their social difficulties by imitating others (social camouflaging), at the cost of an often invisible but real exhaustion; 3) their specific interests may seem more socially acceptable (horses, TV series, animals) than those of boys (trains, dinosaurs, numbers); 4) they are more often wrongly diagnosed as “anxious,” “depressed,” “anorexic,” “hypersensitive” before autism is identified. Consequences: autistic burnout in adolescence, eating disorders (a strong link between anorexia and female autism documented by Westwood and Tchanturia, 2017), severe depression, more frequent suicidal behavior. Specific tools are being developed: the GQ-ASC, the RAADS-R, certain items of the CARS-2 and ADOS-2 are adapted. If you are a woman or a girl who recognizes herself in this description, do not hesitate to request an assessment with a psychologist trained in female ASD.

Sources: Lai and Baron-Cohen, Lancet 2015; Westwood and Tchanturia 2017; international clinical guidelines.

Q19. My child walks on tiptoe — is that a sign?

Toe walking is a sign associated with autism, but not specific to it. It is seen in about 20–30% of autistic children versus 5% of typical children. It can also be seen in dyspraxia, hypertonia, certain neurological conditions, or be entirely benign and transient (idiopathic toe walking). If your child walks on tiptoe occasionally, can put the heel down when asked, has no other sign, and has good psychomotor development, there is probably no cause for concern — but mention it to your pediatrician at the next appointment anyway. On the other hand, if the toe walking is constant, combined with other signs (language delay, withdrawal, sensory particularities, atypical interests), it may be part of a wider autism picture and deserves an evaluation. A physiotherapist can also help, because prolonged toe walking can lead to a shortening of the Achilles tendon. A physiotherapy and podiatry assessment, and possibly a developmental assessment, are worth considering.

Sources: Williams et al., Pediatrics 2012; international clinical guidelines.

Q20. What are the signs in adults?

Many adults live with undiagnosed autism for decades. Clues to recognize: persistent social difficulties (a preference for solitude, intense fatigue after interactions, a feeling of never being “on the same wavelength”), difficulty decoding unspoken cues, humor or innuendo, the sense of having “played a role” all one’s life (masking), intense interests in specific areas (collections, specialized subjects), a strong need for routine and difficulty with the unexpected, sensory hypersensitivities (noise, light, textures, smells), recurrent professional or social burnout, social anxiety, eating disorders, depression, hyperactivity or inattention. Adult diagnosis is carried out by a trained psychiatrist or psychologist, with tools such as the ADOS-2, ADI-R, AAA, RAADS-R. It takes into account early development (interviews with parents if possible), current functioning, and rules out other explanations. Expect waiting times of 12 to 24 months in public services. Putting a word to one’s functioning, at 30, 40, 50 years old, is often an immense liberation and allows a life more in tune with oneself.

Sources: international clinical guidelines for adults; autism resource networks 2023.

Category 3 — The diagnosis

Ten questions to understand the diagnostic process: who to turn to, how it unfolds, how long it takes, and what you will obtain in the end.

Q21. Who should I turn to first if I have doubts?

The first person to talk to is your primary care doctor or your pediatrician. They are the one who can listen to your concerns, observe your child, and refer you to the right services. Your doctor can complete a screening form and direct you toward early-assessment and intervention services. Once accepted, your child can benefit from assessments with a psychomotor therapist, occupational therapist, psychologist or speech therapist, ideally without you having to pay up front, depending on what is available in your country. These early-intervention services do not make the diagnosis but coordinate the evaluations and refer, if needed, toward a local diagnostic team or a specialist autism center. This route avoids the long initial waits and lets you start support even before the ASD is confirmed. Always consult a professional for any decision.

Sources: NDD care pathways; national autism strategies; early-intervention services.

Q22. What is the difference between early-intervention services, specialist centers and diagnostic teams?

Three complementary actors. Early-intervention services are the entry point to the pathway: they receive the doctor's form, organize the first assessments, and refer onward. They do not diagnose. A second-line diagnostic team (hospital teams, day hospitals, child-psychiatry services) is competent to make the diagnosis in the majority of cases, especially for "classic" forms of childhood autism. A specialist autism resource center acts as a third line: it is the regional expert, called upon for complex cases, late diagnoses (adults, adolescents), difficult diagnoses (doubt, comorbidities), and professional training. Such a center is not compulsory in the standard diagnostic pathway, and it is best not to approach it directly for a simple case: its role lies elsewhere, and waiting times there are long (12 to 36 months). First follow the pathway doctor > early-intervention services > diagnostic team, and only go to a resource center on referral.

Sources: international clinical guidelines; resource-center frameworks; autism resource networks 2023.

Q23. How long does it take to obtain a diagnosis?

Waiting times unfortunately remain long, despite the efforts of national autism plans. On average, expect 6 to 18 months between the first concern and the confirmed diagnosis, with enormous regional disparities (3 months in some well-resourced services, more than 2 years in others). Going through early-intervention services considerably reduces these delays and lets you start rehabilitation without waiting for the formal diagnosis. For adults, the wait in public specialist services is 12 to 24 months on average. For complex or late childhood diagnoses (with doubt, comorbidities), also expect 12–18 months. What to do during the wait? Above all: do not wait. The guidance is very clear: as soon as there is clinical doubt, you begin rehabilitation (speech therapy, psychomotor therapy), you provide support, you stimulate. The child does not need to wait for a piece of paper to benefit from help. If you can afford it, a private assessment (a psychologist trained in the ADOS-2) can speed up the diagnosis — expect a cost depending on the assessments requested. Medical advice is essential for any decision.

Sources: international clinical guidelines; early-intervention services; autism resource networks 2023.

Q24. What examinations are done to diagnose autism?

The diagnosis of autism rests on a multidisciplinary clinical evaluation, never on a single test or a single consultation. It generally combines: an in-depth interview with the parents about early development (the ADI-R questionnaire, about 2 hours), a direct, structured observation of the child via the ADOS-2 (Autism Diagnostic Observation Schedule, the international gold standard, about 45 minutes), an assessment of intellectual functioning adapted to age and verbal level (WISC-V, WPPSI-IV, Brunet-Lézine, Leiter for children with little speech), a language assessment by a speech therapist, a psychomotor assessment, sometimes a sensory and neuropsychological assessment, and a physical examination (hearing, vision, genetics, neurology). Depending on the picture, additional tests may be proposed: karyotype, fragile-X testing, brain MRI, EEG. These examinations aim to rule out specific medical causes and to better understand the child's particularities. The diagnosis is made by a physician (child psychiatrist, pediatrician, neuropediatrician, psychiatrist) after synthesizing all of these evaluations.

Sources: international clinical guidelines; ADOS-2 manual 2012; research-institute data 2023.

Q25. Is the diagnosis permanent?

ASD is a lifelong neurodevelopmental condition, so yes, the diagnosis is there to stay. However, the expression of autism can change considerably with age and support. Some children diagnosed at age 3 with "severe" autism and little language will present, at age 12, a much more subtle picture after several years of intensive rehabilitation (this is called an "optimal trajectory" in the literature, Fein et al. 2013). They remain autistic but their symptoms meet the criteria less fully. Conversely, certain difficulties can worsen in adolescence (anxiety, challenging behaviors) if support has been interrupted. The diagnosis is therefore not a fixed verdict but a compass. It should be reassessed periodically (ideally at key transitions: starting school, secondary school, sixth form, adulthood), notably to adapt the support plan, both educational and medico-social. For adults, a new assessment may be needed to claim rights or clarify the picture if the first diagnosis dated back to childhood.

Sources: Fein et al., J Child Psychol Psychiatry 2013; international clinical guidelines.

Q26. How much does a diagnosis cost?

Through public services, the diagnosis is often free or low-cost for the family, depending on your country's health system. This is the route to favor. The downside: waiting times are long. In the private sector (independent psychologist, specialized physician, clinic assessments), expect a significant fee for a complete assessment, generally not reimbursed by public health insurance (except medical consultations). Some private insurers reimburse part of psychological assessments. If you go through early-intervention services, the psychomotor, speech and psychological assessments may be fully covered for a period. For adults, an assessment in a public specialist center is usually free; in the specialized private sector, expect a substantial fee. Financial help may be possible through the disability support available in your country once the diagnosis is made. Ask your social services, your insurer, and a local social worker for advice.

Sources: international clinical guidelines; early-intervention services; national disability support schemes.

Q27. Should I seek a diagnosis even if my child is doing fairly well?

A legitimate question. The answer: yes, in the vast majority of cases. Even for a child who adapts fairly well, obtaining a diagnosis allows you to: 1) explain their particularities to those around them and to themselves ("I'm like this, not weird"); 2) anticipate critical periods (changing schools, adolescence, adult life); 3) access educational accommodations and workplace recognition; 4) prevent secondary difficulties (anxiety, depression, autistic burnout) that often arise when autism goes unnoticed; 5) benefit from disability-related rights if needed. The diagnosis is not a label that sticks; it is a tool for understanding and action. That said, some parents prefer to wait and see: that is respectable, especially if the child is neither suffering nor in major difficulty. Discuss it with their doctor. And know that the diagnosis remains accessible later, at any age — there is no window that closes. Medical advice remains essential for deciding.

Sources: international clinical guidelines; Lai and Baron-Cohen, Lancet 2015.

Q28. How do I tell my child about the diagnosis?

There is no single right age, nor any universal way of putting it. The general rule: be honest, simple, factual, and adapt to the child's age and understanding. Around 5–7 years, you can speak of "a brain that works a little differently, which makes some things easy and others harder." Around 8–10 years, the word "autism" can be named, placing it within a plurality ("there are many autistic people; with some you wouldn't even notice it, others need more help"). In adolescence, the young person often asks to understand. Give positive, concrete examples, show role models (books for young people, accounts by autistic teenagers and adults), allow questions over time. Avoid: phrasings like "you're sick," "you're special" (vague), "you'll have to be cured." Favor: "you're one of the people who think differently, and we're learning together." Many resources exist: youth books and TV series featuring autistic characters. The advice of a trained psychologist remains valuable.

Sources: international clinical guidelines; research-institute data 2023.

Q29. What should I do if I'm refused a diagnosis?

This still happens, unfortunately. Some professionals minimize ("he's just shy," "she'll talk later," "boys are like that"), others fear "labeling." If you are convinced of the relevance of an assessment, here is what to do: 1) Ask for a second opinion: change pediatrician, consult a neuropediatrician or a child psychiatrist trained in neurodevelopmental disorders. 2) Approach your regional early-intervention services directly: they can sometimes accept a referral even without a medical recommendation. 3) Contact your national autism association for guidance. 4) Document: keep a journal of dated, precise observations, film if possible, list the signs. These elements are precious for future assessments. 5) Join associations: their advisers know the regional circuits and can guide you. Your parental intuition counts.

Sources: international clinical guidelines; national autism strategies; autism associations 2024.

Q30. Can the diagnosis change or be revised?

Yes. An autism diagnosis made at age 3 is not immutable. It can be revised for several reasons: 1) initial error (rare but possible, notably in children with sensory, language or attentional difficulties that mimicked autism but were not autism); 2) clarification of the picture in adolescence or adulthood with more suitable tools; 3) major clinical evolution (optimal trajectory, where the criteria are no longer fully met); 4) addition or removal of associated diagnoses (ADHD, intellectual disability, language disorders). A reassessment is useful at key moments: starting primary school, secondary school, sixth form, age 18 (adult transition), or before a request for disability-related rights. It can be carried out in a specialist center, by a psychiatrist or a specialized psychologist. Important: revision is not about “lifting” the diagnosis in order to “pass for normal.” It is about updating the understanding of a person who is evolving, and adapting their support.

Sources: international clinical guidelines; Fein et al. 2013; autism resource networks 2023.

> Valentine’s reflection: “On diagnosis day, someone handed me a sheet of A4 paper with a single word on it. I would have wanted someone to first hold out their hand. That’s why I write today: to hold out that hand.”

Category 4 — Support methods

Ten questions to understand the main approaches, their scientific basis, and the official positions on each.

Q31. What is the ABA method?

ABA (Applied Behavior Analysis) is an approach derived from behavioral psychology, developed in the 1960s by Ivar Lovaas. It rests on the idea that behaviors are learned and can be taught by breaking each skill (looking, imitating, requesting, waiting, sharing) into small steps that are positively reinforced. Early, intensive ABA intervention (15–30 hours per week) in young children has shown documented effectiveness on language development, adaptive skills and the reduction of problem behaviors (meta-analyses Reichow et al., Cochrane 2018; Smith and Iadarola, J Clin Child Psychol 2015). Clinical guidelines classify behavioral and developmental interventions (including ABA and ESDM) among the recommended interventions. Modern ABA (sometimes called verbal-behavior ABA, naturalistic ABA) has evolved: less repetitive drilling, more intrinsic motivation, more respect for the child's interests. Choose a certified BCBA practitioner or someone supervised by a BCBA, and favor ethical approaches based on the child's assent.

Sources: international clinical guidelines; Reichow et al., Cochrane 2018; Smith and Iadarola 2015.

Q32. What is the Denver model (ESDM)?

The ESDM (Early Start Denver Model) is a developmental and behavioral approach designed by Sally Rogers and Geraldine Dawson in the early 2000s, specifically for very young children (12 to 48 months). It draws on the contributions of ABA but integrates them into a profoundly developmental and relational framework: work is done through play, following the child's interests, fostering quality interactions with parents and practitioners. The goal is to take advantage of early brain plasticity to stimulate the development of communication, language, emotions and social skills. A landmark study by Dawson et al. (Pediatrics 2010) showed significant gains in IQ and adaptation in ESDM children compared with a control group, with an observable reduction in certain autistic symptoms. The ESDM is classified among the recommended interventions. It is delivered in private practice, in early-care centers and in day hospitals, by certified ESDM practitioners. It is one of the few manualized approaches validated in very young children.

Sources: Rogers and Dawson, ESDM 2010; Dawson et al., Pediatrics 2010; international clinical guidelines.

Q33. What is TEACCH?

TEACCH (Treatment and Education of Autistic and related Communication-handicapped CHildren) is a structured educational program developed in the 1970s by Eric Schopler at the University of North Carolina. Its central principle: harness the visual strengths and the need for predictability of autistic people to enable them to understand and act within their environment. Concretely: structuring space (a corner for each activity), structuring time (visual schedules), structuring work (activity boards, visual binders), visual supports (pictograms, photos, sequences). TEACCH is not a method for "learning to talk": it is an overall educational framework that reduces anxiety, fosters autonomy, and combines very well with other approaches (ABA, ESDM, PECS, Makaton). It is considered a recommended framework. TEACCH supports are today used in most specialized educational settings and inclusion classrooms. For families, short training courses exist (through resource centers, associations) that help adapt the home environment.

Sources: Schopler, Mesibov, TEACCH 2005; international clinical guidelines; Virues-Ortega et al., 2013.

Q34. What is the "3i" method?

The "3i" method ("Intensive, Individual, Interactive") was developed in the early 2000s, drawing on the work of Stanley Greenspan (the Floortime method). It proposes full-time home-based support, run by 30 to 40 rotating volunteers, in a dedicated room, to stimulate the child through play, following their interests and building connection. An important point: clinical guidelines have NOT retained the 3i method as a recommended intervention, for lack of scientific evidence of effectiveness validated by controlled studies. It is not banned, but it does not have the status of a validated intervention. Some parents report benefits; others denounce a significant financial and organizational cost (recruiting and training volunteers, enormous family mobilization), and sometimes an interruption of schooling. If you are considering the 3i, read the available reviews carefully, ask about results at 5 years, and keep validated approaches running in parallel (speech therapy, psychomotor therapy). Medical advice is essential.

Sources: international clinical guidelines; method documentation 2024.

Q35. What is the Son-Rise method?

The Son-Rise Program was created in the United States in the 1970s by Barry and Samahria Kaufman based on their parental experience. It is a relational approach that proposes to "join the child in their world": if the child lines up cars, the parent also lines up cars beside them; if they rock, you rock too. The idea is to create a reassuring bond before expecting any interaction. The method emphasizes attitude (joy, energy, optimism, presence). Clinical guidelines do not retain Son-Rise as a recommended intervention: to date there are no quality controlled studies demonstrating its effectiveness. The reported benefits are mainly familial (reduced parental stress, stronger bond) rather than measurable developmental gains. The program is purchased as paid (often expensive) training courses, at the Autism Treatment Center of America. If you are considering it, keep validated interventions running in parallel (speech therapy, psychomotor therapy, a developmental behavioral intervention such as ESDM). As always, discuss it with a physician and a psychologist trained in ASD.

Sources: international clinical guidelines; Williams and Wishart, Br J Spec Educ 2003.

Q36. What is the official position on the various methods?

Major health authorities have published and updated guidelines on autism interventions. The summary position: recommended interventions ("coordinated, comprehensive, structured and early intervention, to be started before age 4") primarily include behavioral, developmental and educational approaches — notably ABA, ESDM, the TEACCH program, PECS, Makaton, and modernized Lovaas-type interventions. Also recommended are: speech therapy, psychomotor therapy, occupational therapy, and interventions for comorbidities (sleep, feeding, anxiety). NOT recommended (for lack of evidence of effectiveness) or not consensual are: psychoanalysis as the main form of care, the 3i method, packing (formally advised against), Son-Rise, and gluten-free/casein-free diets as a systematic intervention. The guidelines stress the importance of active parental participation, a personalized plan, and reassessment every 12 months. Always seek guidance from a trained physician.

Sources: international clinical guidelines on ASD.

Q37. Packing and psychoanalysis — where do things stand?

Packing — wrapping the child in cold wet sheets — was used in certain day hospitals as a “therapy” for autistic children. It has been formally advised against: there is no evidence of effectiveness, and it poses a risk to the child. Several ethics committees and the UN (Committee on the Rights of Persons with Disabilities, 2015) have called for its cessation. Its use is now banned. As for psychoanalysis: long central in some countries’ approach to autism (with theories now rejected, such as Bettelheim’s “refrigerator mother”), it is no longer recommended as a main intervention. It has not proven any effectiveness superior to developmental and behavioral interventions. Many settings have transitioned toward recommended approaches, but disparities persist. If these approaches are proposed to you as the sole intervention, ask for access to validated interventions in addition or as a replacement, and turn to a specialist autism center.

Sources: international clinical guidelines; UN CRPD 2015; national autism strategies.

Q38. Is a gluten-free, casein-free diet necessary?

A real question, asked by a great many families. The current scientific answer is nuanced but firm: to date, there is no solid evidence that a gluten-free, casein-free (GFCF) diet is systematically effective on autism symptoms. A Cochrane review (Millward et al., 2008, updated) and several meta-analyses (Sathe et al., Pediatrics 2017; Piwowarczyk et al., Eur J Nutr 2018) conclude that the level of evidence is insufficient. Health authorities do not recommend systematically putting a GFCF diet in place. However, some autistic children do have digestive problems, a confirmed gluten intolerance (coeliac disease, to be diagnosed with a gastroenterologist), or food allergies: in those specific cases, and after medical advice, an adapted diet may be indicated. Do not put a child on a restrictive diet without medical supervision: nutritional risks (iron, calcium, B12 deficiencies), worsening of food selectivity, anxiety around meals. If you want to test it, do so with a nutritionist, for a limited period, objectively evaluating the effects.

Sources: Sathe et al., Pediatrics 2017; Piwowarczyk et al. 2018; international clinical guidelines.

Q39. How do I choose the right method for my child?

There is no universal method. A good intervention for your child meets several criteria: 1) It is scientifically validated: ABA, ESDM, TEACCH, speech therapy, psychomotor therapy, occupational therapy. 2) It is early (ideally before age 4) and structured. 3) It is part of a written, personalized plan, reassessed every 6 to 12 months. 4) It involves parents (as co-therapists, with parental guidance support). 5) It respects the child's dignity, without resorting to restraint, punishment or traumatic procedures. 6) It combines well with schooling, which is a right. 7) It is delivered by trained professionals (certifications, qualifications, supervision). In practice, several approaches are often combined: ESDM or ABA for global development, speech therapy for communication, psychomotor therapy for the body, TEACCH for daily structure, sometimes PECS or Makaton for alternative communication. The advice of the referring physician should always guide the choices.

Sources: international clinical guidelines; research-institute data 2023.

Q40. How many hours of support are recommended?

For a young child (before age 6), guidelines and the international literature recommend an early intensive intervention: 20 to 25 hours per week of structured intervention, involving all the actors (specialized practitioners, parents, school if enrolled, private professionals). This may seem enormous — and it is often hard to achieve in practice, for lack of places in services and trained professionals. In reality, the total combines: the main intervention (ABA, ESDM, TEACCH) — 10 to 20 h/week; speech therapy — 1 to 3 sessions/week; psychomotor therapy — 1 to 2 sessions/week; generalization at home by the parents — a few hours per day. For older children (from 6–8 years), the intensity can decrease, focusing on targeted objectives: social skills, autonomy, communication, schooling, anxiety management. For adolescents and adults, support remains useful but shifts toward coaching, employment integration, and psychological support. Important: quality matters more than quantity. 10 hours of relevant intervention are worth more than 25 poorly coordinated ones.

Sources: international clinical guidelines; Dawson et al. 2010; Reichow et al., Cochrane 2018.

> Valentine's reflection: "I came across every method. The only one that worked at home was the one I built with my son, drawing on several of them. No method works if it isn't adopted by the family."

Category 5 — Schooling

Ten questions about education: from the right to attend school to specialized arrangements, from accommodations to possible appeals.

Q41. Can my autistic child attend mainstream school?

Yes. In most countries, the law affirms the right to mainstream education for all children with disabilities, including autistic children. Schooling can take several forms depending on needs: 1) individual enrollment in a mainstream class (preschool, primary, secondary), with or without a teaching assistant or support worker; 2) enrollment in an inclusive arrangement — a dedicated class within a mainstream school; 3) enrollment in a specialized teaching unit (an autism-specific preschool or primary unit); 4) shared enrollment with a specialized educational establishment or day hospital. The choice depends on the child's profile, the local provision and the family's plan, formalized in a personalized education plan. No child should be excluded from school without an alternative solution.

Sources: disability-rights legislation; national autism strategies; inclusive-education guidelines.

Q42. What is a teaching assistant / support worker, and how do I obtain one?

A teaching assistant or support worker is a professional who accompanies one or more pupils with disabilities during school hours. Their role: help with time management, concentration, social interactions, the use of adapted materials, and sometimes basic care (toileting, meals for the youngest). There are several formats: individual (for a single pupil), shared (between several pupils in a class or establishment), and collective (in an inclusive class). To obtain one, you must apply to the disability/education authority in your country: your child needs an open file and a notification of human support included in their education plan. The authority assesses, and the education service recruits. Waiting times vary widely. A difficulty: despite the notification, the actual recruitment of a support worker is not always immediate (national shortages are common). If your child has a notification but no support worker, contact your local education authority and report it.

Sources: education services; international clinical guidelines; disability/education authorities.

Q43. What is an inclusion class?

An inclusion class is an arrangement that allows pupils with disabilities to be educated within a mainstream establishment, while benefiting from adapted support. Versions exist for primary (roughly 7–11 years), secondary (11–15 years), and upper-secondary (15–18 years). Reduced class size (10 to 12 pupils), a specialized teacher, a shared support worker. The pupil spends part of their time in the inclusion class (adapted, slower, more visual learning), and part in a mainstream class with their own age group (according to their abilities). Inclusion classes often bring together several profiles: autism, intellectual disability, language disorders, psychological difficulties. This is debated:

some parents would prefer an "autism-specific" inclusion class (still rare). A place is obtained through the disability/education authority (an education plan with an inclusion-class recommendation). Waiting times can be long, with major territorial inequalities. Inquire with your local education authority.

Sources: education services; international clinical guidelines.

Q44. What are autism-specific teaching units and self-regulation arrangements?

These are recent arrangements designed to educate young autistic children within a mainstream school, with intensive supervision. An autism-specific preschool unit: a class of about 7 autistic children aged 3–6, within a mainstream preschool, staffed by a specialized teacher, an educator, a support worker, a psychologist, a speech therapist, a psychomotor therapist, supervised by a physician. Around 25 hours of weekly support combining schooling and interventions. An autism-specific primary unit: the equivalent for 6–11 year olds. A self-regulation arrangement: a newer, inclusive setup in which the autistic child is in a mainstream class with a pair of specialized practitioners (a specialized teacher + an educator trained in ABA/TEACCH) who work both in the class and one-to-one. All these arrangements are accessed through the disability/education authority, after assessment. Provision is still insufficient against demand. Inquire with your national autism association and disability/education authority.

Sources: national autism strategies; education services.

Q45. What are specialized educational establishments and home-based support services?

A specialized educational establishment is a medico-social setting that takes in children and adolescents (roughly 6–20 years) with disabilities, most often as boarders or day attendees. It offers adapted schooling (a teaching unit), care (psychomotor therapy, speech therapy, medical and psychological follow-up), and educational support. This is a major orientation, which suspends mainstream schooling — to be considered only if mainstream education is impossible despite accommodations. Autism-specialized establishments are becoming more numerous. A home-based support service is the opposite option: it intervenes at home and/or at school, alongside mainstream schooling. A multidisciplinary team (educator, psychologist, speech therapist, psychomotor therapist) supports the child a few hours a week. Such a service is extremely valuable for sustaining inclusion. Both arrangements require an orientation from the disability/education authority. Waiting times can range from a few months to several years, depending on the region and the scarcity of places.

Sources: national disability agencies 2024; international clinical guidelines.

Q46. What is a personalized education plan?

A personalized education plan is the official document that formalizes the accommodations and the school pathway of a pupil with a disability. It is drawn up by the disability/education authority's multidisciplinary team after assessing the file, based on a standardized school-evaluation tool. It specifies: the placement (mainstream class, inclusion class, teaching unit, specialized establishment), the pedagogical accommodations (extra time, adapted materials, visual supports), the human support (individual or shared support worker, number of hours), the rehabilitation during school hours (speech therapy, psychomotor therapy, occupational therapy), and exam accommodations (extra time, a scribe, a computer). It is reviewed each year at a follow-up meeting that brings together parents, teachers, support workers, care professionals and a referring coordinator. As a parent, you have the right to take an active part in all these meetings, to request changes, and to challenge decisions if needed. The plan differs from medical-only plans, light learning-difficulty plans, and temporary in-school support programs.

Sources: education services; disability/education authorities.

Q47. What is the difference between the various school plans?

Several arrangements are often confused. A personalized education plan is intended for pupils recognized as having a disability, and opens the right to substantial accommodations and to a support worker. A medical care plan concerns pupils with a chronic health condition (asthma, allergy, diabetes, epilepsy): it defines the medical protocols at school and is not tied to a recognized disability. A learning-accommodation plan is intended for pupils with a learning disorder (the “dys-” conditions) without formal disability recognition: it allows pedagogical accommodations (extra time, computer, oral reading, copies of the board) without going through the disability authority. It is validated by the teacher and the school doctor. An in-school support program is internal to the school, for a pupil with temporary academic difficulty: it has nothing to do with a disability. For an autistic child, the personalized education plan is generally the relevant route, sometimes combined with a medical care plan (if there is treatment). Medical advice and a disability file are needed.

Sources: education services; disability/education authorities.

Q48. Can my child attend a private or independent school?

Yes, you have the right to enroll your child in a state-contracted private school (which should in principle accept children with disabilities on the same terms as the public sector, with the education plan applicable) or in a fully independent school (Montessori, Steiner, various alternative schools). Note: independent schools have no obligation to admit, do not receive publicly funded support workers, and are not required to apply the education plan. You can nonetheless fund a private support worker — but the cost is significant. Some autism-specialized schools (ABA schools, TEACCH-method autism schools) are independent, sometimes partly funded through disability-support schemes or charitable grants. Inquire precisely: annual cost, educational project, staff qualifications, any accreditation. Before leaving the public system, explore all the options (inclusion classes, autism-specific units, self-regulation arrangements, home-based support services).

Sources: disability-rights legislation; national disability agencies 2024.

Q49. Is home education possible?

Yes, but it is increasingly regulated. In many countries home education has become a regime of authorization rather than a simple declaration: you must submit a reasoned request to the relevant education authority before each school year. For a child with a disability, the ground of “a situation specific to the child motivating the educational project” is often explicitly provided for. The file must include: an educational project, resources, a calendar, medical supporting documents. Once authorization is granted (renewable), annual checks take place. Home education may be relevant for a child in great school-related distress, or while waiting for a specialized place. It has a high cost in parental mobilization (often one parent reducing their work), and it can socially isolate the child. Consider it as a temporary solution with a plan to return to school, and always combined with rehabilitation and specialized follow-up.

Sources: home-education legislation; education services.

Q50. What should I do in case of refusal of schooling or bullying?

No child may be excluded from school because of their disability. If you encounter a refusal of schooling, here are the avenues: 1) Contact the referring coordinator for your area, who is the official point of contact; 2) Request an educational team or follow-up meeting promptly, by registered letter; 3) Approach your local education authority; 4) Approach the inclusive-education unit of your regional education department; 5) Refer the matter to your national ombudsman or rights defender (free, by post or online); 6) As a last resort, an administrative or legal appeal. Regarding bullying: many countries have a national helpline and an anti-bullying protocol — ask your school or your national autism association. Autistic children are 3 to 5 times more exposed to school bullying (Maïano et al., 2016): stay vigilant, believe your child, document (dates, facts, witnesses). Silence always makes the situation worse.

Sources: disability-rights legislation; ombudsman services; Maïano et al. 2016.

Category 6 — Administrative steps

Ten questions to untangle disability authorities, allowances and support: what you are entitled to, how to obtain it, and how to appeal in case of refusal.

Q51. What is a disability authority?

In most countries there is a single point of contact for disability-related matters — a department or agency that brings together all the steps linked to disability. Its role: to assess the disability, open rights, and provide guidance. It is generally the body that decides on the allocation of disability allowances, compensation for disability-related costs, employment recognition for adults, mobility/parking cards, and educational and medico-social orientation (inclusion classes, specialized establishments, teaching units), including the notification of a school support worker. The disability file is usually a single file to submit to the authority for your place of residence. Official processing times vary, but in practice are often several months. All decisions can be challenged (usually a prior administrative appeal followed by a tribunal). Do not hesitate to ask associations for help in putting your file together.

Sources: disability-rights legislation; national disability agencies 2024.

Q52. How do I put together a disability file?

A disability file is usually made up of several elements. 1) An administrative form (information, a “life plan” — a very important section to take care over: describe daily life, the concrete difficulties, the needs — and precise requests). 2) A recent medical certificate completed by a physician (general practitioner, pediatrician, child psychiatrist, neurologist). 3) Supporting documents: identity, proof of address, family record, assessments (psychological, speech, psychomotor, occupational-therapy, school), medical reports, a school-evaluation form if enrolled. Tips: 1) Be precise and concrete in the life plan (“my child needs help to dress, eat, move around independently,” rather than “he is autistic”); 2) Gather ALL the assessments before sending; 3) Make copies of everything; 4) Send by registered post; 5) Renew in advance (3–6 months before expiry). A social worker can help you.

Sources: official guidance; national disability agencies.

Q53. What is a disabled-child education allowance?

A disabled-child education allowance is financial support paid to the parents of a child under 20 with a disability whose degree of incapacity is recognized by the disability authority at a sufficient threshold. There is usually a base amount, paid without means testing, to which supplements can be added depending on: 1) the nature and severity of the disability; 2) the need for a parent to reduce or stop their activity; 3) the recourse to a third party; 4) the specific expenses incurred. The supplements vary considerably. In some systems you can choose between the base allowance plus a supplement, or the base allowance plus a disability-compensation benefit (often more advantageous if needs are heavy). Ask your disability authority or a social worker for a simulation. Such allowances are generally non-taxable and not counted toward other social benefits.

Sources: family-benefits agencies 2024; national disability agencies.

Q54. What is a disability-compensation benefit?

A disability-compensation benefit is financial support intended to cover the extra costs linked to disability: human support (a personal-care assistant, specialized practitioners, ABA, ESDM), technical aids (adapted materials), home and vehicle adaptation, animal assistance, specific charges (nappies beyond a certain age, adapted clothing). It is generally intended for people whose difficulties are recognized by the disability authority. It is accessible to children — either combined with a base education allowance, or in place of a supplement. The calculation is complex and individualized: it can reach a substantial monthly amount for a child requiring significant daily support. Such a benefit can fund home-based ABA practitioners, specialized educational outings, sensory equipment (a weighted blanket, noise-cancelling headphones). It is usually non-taxable. Ask the disability authority or a social worker for a comparative calculation before choosing.

Sources: national disability agencies 2024; regional councils; disability authorities.

Q55. What is employment recognition, and when should I request it?

Employment recognition for people with disabilities is a step intended for adults (usually from age 16) who wish to have it recognized that their disability has an impact on their ability to work. It does not say that one is unfit for work: on the contrary, it opens rights to facilitate access to and retention in employment: 1) access to adapted enterprises, sheltered workshops, and disability schemes in public service; 2) workstation adaptation, extra time in competitive exams, employment support (equipment, training, human support); 3) priority in redeployment, protection against certain dismissals; 4) early retirement if conditions are met; 5) access to specialized employment services and adapted vocational training. To request it: complete the disability file with a medical certificate. Validity varies. It does not appear on the CV or in the employer’s file unless declared voluntarily. It is an asset, not a stigma. Ask a social worker or a specialized employment service to support you.

Sources: disability authorities; employment-support agencies.

Q56. What is an adult disability allowance?

An adult disability allowance is financial support paid to people aged 20 and over (or 16 in certain cases) whose degree of incapacity recognized by the disability authority reaches a high threshold, or a medium threshold combined with a substantial and lasting restriction on access to employment. There is generally a maximum monthly amount. In some systems the allowance was long calculated taking the partner’s income into account; reforms have moved toward counting only the income of the person with the disability — a major step forward for autonomy. The allowance can be combined with other support: a resource supplement, an independent-living top-up, housing assistance. It is granted for a period (sometimes for life if the situation is stable). The request is made through the disability file. It is one of the most structuring forms of support for autistic adults.

Sources: family-benefits agencies 2024; national disability agencies; disability authorities.

Q57. What is a mobility / inclusion card?

A mobility or inclusion card typically replaces older invalidity, parking, and priority cards. It often exists in three forms: 1) An invalidity card: for people whose degree of incapacity reaches a high threshold; it can give tax advantages, priority in queues and on transport, and free or reduced public-transport fares depending on the city. 2) A parking card: allows free parking in disabled spaces (and sometimes any paid on-street parking), without time limit; useful for autistic children who have sensory or behavioral difficulties when out. 3) A priority card: for people below the high incapacity threshold but for whom standing is difficult; priority in queues and for seats. The request is made through the disability file. Waiting times vary; validity can extend up to many years (sometimes for life). Make this request as soon as the diagnosis is made: it makes daily life (doctors, hospitals, outings) much easier.

Sources: national disability agencies; disability authorities.

Q58. How do I obtain a notification for a school support worker?

A notification of human support (a school support worker) is obtained through the disability file. Steps: 1) Put together a complete disability file, explicitly requesting “human support in the school setting” in the life plan; 2) Attach the medical certificate, the assessments (speech, psychomotor, neuropsychological, occupational-therapy), and the school-evaluation form completed by the school (teacher and head); 3) Describe concretely what happens at school without support (meltdowns, isolation, inability to follow instructions, wandering, challenging behaviors); 4) Send by registered post. The disability authority assesses, and a rights commission decides. The notification may be for an individual or a shared support worker. Once the notification is obtained, it is the education service that actually recruits. While waiting for the support worker to be in place: report to the referring coordinator, the local education authority, and if necessary the ombudsman. Be patient but firm: it is a right. Renew in advance, by cycle (typically at each change of school cycle).

Sources: disability authorities; education services.

Q59. How do I challenge a disability-authority decision?

If you disagree with a decision (refusal of an allowance, an incapacity rate judged too low, refusal of a support worker, an unwanted placement), you have several avenues. 1) A prior administrative appeal: within a set period after the notification, you write to the authority requesting a review, giving reasons and attaching new elements (new assessments, new certificates, testimonies). This is usually mandatory before any legal action. 2) If the administrative appeal is rejected or unanswered: a legal appeal before the competent tribunal. A lawyer is not always required, but the help of an association or a social worker is precious. 3) For schooling questions (a refusal to apply a notification), also approach the local and regional education authorities, and possibly an administrative court. 4) An ombudsman can be approached at any time, free of charge. Advice: do not give up; the success rate of appeals is far from negligible. Useful: national autism associations and disability-rights organizations.

Sources: social-action legislation; ombudsman services; national disability agencies.

Q60. What should I do when my child comes of age?

Coming of age (18 years) is a key stage that requires several anticipated steps. 1) Six months before the 18th birthday: renew the disability file, requesting adult rights — an adult disability allowance, employment recognition (if there is a professional plan), adult human support (if in higher education), an adult mobility/inclusion card. 2) Assess the need for legal protection: if your young adult cannot manage their affairs alone (administrative, financial, medical), consider a protection measure. Three levels from lightest to strongest: family authorization (flexible, ideal within a family), assisted decision-making, and guardianship/representation. This is handled through the court, with a medical certificate from an approved physician. 3) Post-school orientation: university with accommodations (a disability office), adapted training, sheltered employment, mainstream employment with recognition. 4) Housing: staying at the parental home, a residential home, a medicalized care home, a specialized care home, inclusive housing. Anticipate: places are scarce, ask your national autism association for contacts.

Sources: national disability agencies 2024; disability authorities; courts.

> Valentine’s reflection: “I remember my first time at the disability office: I had prepared all my questions, and I came out with even more questions. Today I know: that’s normal. We learn as we walk.”

Category 7 — Communication and language

Ten questions about speech, the absence of speech, alternative tools, and everything that lets your child make themselves understood.

Q61. My child doesn't speak — is that necessarily autism?

No, not necessarily. The absence or delay of language can have many causes: deafness (always to be checked first with a hearing test, even if the baby seems to react), developmental language disorder, a simple language delay, intellectual disability, bilingualism with a parent who is linguistically little present, an under-stimulating environment, selective mutism (the child speaks at home but not in society). Autism is ONE of the explanations, and it is associated with a language disorder in about 30 to 40% of cases among ASD children. What points to autism rather than a simple language delay: 1) the absence of compensatory gestures (pointing, miming, handing over to show); 2) a broader deficit in non-verbal communication (gaze, facial expressions, joint attention); 3) the presence of other signs (restricted interests, sensory particularities, repetitive behaviors). A speech-and-language assessment by a professional trained in ASD, combined with a psychological assessment, will help decide. Always consult a doctor.

Sources: international clinical guidelines; Tager-Flusberg et al., Brain Lang 2009.

Q62. What is alternative communication?

Augmentative and Alternative Communication (AAC) brings together all the tools and strategies that complement or replace speech for non-verbal or minimally verbal people. It is essential for giving the child a way to express their needs, emotions and choices — and thus to reduce anxiety and challenging behaviors. Several systems exist: 1) Non-technological communication: pictograms (PECS, Makaton pictograms, a communication binder), manual signs (Makaton, sign language); 2) Technological communication: tablets with dedicated apps (Proloquo2Go, LetMeTalk, GoTalk, TD Snap), voice output; 3) Mixed communication (gesture + image + sound). AAC never prevents the emergence of speech: on the contrary, several studies (Schlosser and Wendt, 2008; Romski et al., 2010) show that it fosters spoken language. Too many parents and professionals still wrongly fear that "if we give him pictograms, he'll never speak." That is false. Put AAC in place as soon as possible, with the speech therapist.

Sources: Schlosser and Wendt 2008; international clinical guidelines; Romski et al. 2010.

Q63. What is PECS?

PECS (Picture Exchange Communication System) is a communication system based on exchanging pictures, developed in 1985 by Andy Bondy and Lori Frost in the United States. It teaches the child to initiate communication by handing a picture to a partner in order to obtain what they want. The method has 6 progressive phases: 1) Physical exchange of a picture for a desired object; 2) Distance and persistence; 3) Discrimination between pictures; 4) Sentence structure ("I want + object"); 5) Responding to "What do you want?"; 6) Spontaneous commenting ("I see," "I hear"). PECS is widely used and recognized. It is particularly suited to minimally verbal children, or as a step toward spoken language. Studies show that it fosters the emergence of speech in about 40–50% of trained children (Tincani 2004; Sulzer-Azaroff et al., 2009). Training for parents and professionals is provided by Pyramid Educational Consultants (paid courses). PECS is set up with a speech therapist or trained educator. Expect 6–18 months for the first phases.

Sources: Bondy and Frost, PECS 2001; Tincani 2004; international clinical guidelines.

Q64. What is Makaton?

Makaton is a multimodal communication program that combines speech, manual signs and pictograms. Created in the 1970s in the United Kingdom by Margaret Walker, it is used for children and adults with language and communication difficulties (autism, Down syndrome, intellectual disability, language disorders). Features of Makaton: 1) you ALWAYS speak at the same time as you sign (it is not a separate language like sign language); 2) you sign the key words of the sentence, not every word; 3) the vocabulary is structured into 8 progressive levels (450 signs/pictograms in total); 4) visual supports accompany learning (workbooks, binders, apps). Makaton fosters understanding, expression, and often the emergence of spoken language. Training is available for parents and professionals. Expect a few days of training for the first levels. It is one of the most widely used tools in specialized settings and inclusion classes. Very complementary with PECS and pictograms.

Sources: Walker M., Makaton 1973; Makaton training organizations; international clinical guidelines.

Q65. What is the difference between Makaton and sign language?

Two different systems often confused. Sign language is a full language in its own right, with its own grammar, spatial syntax, and a lexicon of several thousand signs. It is the native language of the Deaf community. It is practiced in silence (without parallel speech). Learning sign language means learning a new language (count several hundred hours for an intermediate level). Makaton, by contrast, is not a language: it is a communication-support program. It borrows certain signs from sign language, but you ALWAYS speak at the same time as you sign, you sign only the key words, and the vocabulary is limited to 450 progressively structured signs/pictograms. It is learned in a few days of training. For a non-verbal autistic child: sign language is demanding (useful if the household is Deaf), whereas Makaton is more accessible. You can also simply use pictograms (PECS, Sclera, ARASAAC) without signs. The choice depends on the child, the speech therapist, and consistency with those around them.

Sources: Makaton training organizations; sign-language federations; international clinical guidelines.

Q66. My child does echolalia — is that serious?

Echolalia is the repetition of words, phrases or intonations that have been heard, either immediately after hearing them (immediate echolalia: you say “Do you want some milk?” and they answer “Do you want some milk?”), or later (delayed echolalia: they repeat a line from a cartoon heard the day before). Very common in autistic children (60–75%), echolalia was long considered a symptom to be extinguished. The view has changed:

echolalia has a communicative function. It allows the child to request, to comment, to reassure themselves, to keep contact, to learn the language. An echolalia may mean “yes I want” (reusing the question as a request), “I want it to be like in the cartoon,” “that’s what Daddy always says when he comes home.” The strategy is not to extinguish it, but to DECODE what the child is expressing, and to offer adapted rephrasings. A speech therapist trained in ASD can help you. Over time, many children move from pure echolalia to spontaneous language — echolalia is often a step on the path to their own language.

Sources: Prizant and Duchan 1981; Stiegler 2015; international clinical guidelines.

Q67. Should I force my child to speak?

No, forcing does not work, and it is even counterproductive. Speech emerges when the child feels the need for it and has the neurological capacity. Forcing (“say hello,” “repeat after me,” “you won’t get it until you’ve said it”) creates stress, opposition, sometimes a lasting block. What really helps: 1) Give the child a way to communicate even without speech (PECS, signs, pictograms, tablet) — communication comes first, speech can follow; 2) Stimulate joint attention: show, share, comment aloud on what they are doing; 3) Create situations that motivate communication (put a desired object out of reach so they ask for it); 4) Use visual supports (books, gesture rhymes, videos to imitate); 5) Work with a speech therapist trained in ASD, not alone; 6) Model language by speaking clearly, slowly, with short adapted sentences. Patience and consistency. Many children begin to speak between 4 and 7 years old, sometimes later. No age limit is definitive.

Sources: international clinical guidelines; Kasari et al. 2014; Tager-Flusberg 2009.

Q68. My child speaks well but doesn’t understand humor or irony — why?

This is a frequent feature of autism, including in people with very developed language: the difficulties bear less on language itself than on pragmatics (the use of language in context). Understanding irony, sarcasm, innuendo, figurative expressions (“it’s raining cats and dogs,” “I’m dying of laughter”), puns, deliberate contradictions, requires decoding what is NOT said, inferring the other’s intention, and mobilizing what is called “theory of mind.” The latter is often atypical in autistic people (Baron-Cohen et al. since 1985). As a result: your child may take expressions literally, not see that someone is joking, take offense at a harmless tease, miss an implicit instruction (“it’s hot in here” = “open the window”). This can be worked on: social-skills workshops, explanatory books, training with parents, speech-therapy sessions focused on pragmatics. Patience and explicitness: say things directly, explain jokes afterward. Over time, these skills sharpen.

Sources: Baron-Cohen et al. 1985; international clinical guidelines.

Q69. What is language pragmatics?

Pragmatics is the dimension of language that concerns its use in situation: how you speak to someone, in what context, with what intention, respecting which implicit social rules. It includes: taking turns to speak, looking at your interlocutor, adjusting your tone to the situation (different at home and at the doctor’s), understanding unspoken cues, humor, figurative expressions, innuendo, knowing how to introduce a topic, close it, change subject without breaking the conversation, knowing what to tell whom. In autistic people, this is often the most difficult side of language — even when vocabulary and grammar are excellent. Daily consequences: monologues on favorite subjects without noticing the other's boredom, conversations that "bounce" out of step, frequent misunderstandings, the feeling of never being on the same wavelength, intense fatigue after an interaction. This can be worked on in specialized speech therapy (pragmatics), in social-skills workshops, with visual supports (Carol Gray's social stories). Patience and consistency.

Sources: Tager-Flusberg, Brain Lang 2009; Carol Gray 2010; international clinical guidelines.

Q70. My child has selective mutism — is that autism?

Not necessarily. Selective mutism is a distinct anxiety disorder (DSM-5): the child speaks normally in certain situations (at home, with their parents) but stays completely silent in others (at school, with strangers, in society), consistently and lastingly (more than a month), with real distress. It often begins between 3 and 6 years, and affects about 1% of children. It is an anxiety disorder, not defiance or a tantrum. That said, it can coexist with ASD, and the two situations can overlap: a very anxious autistic child can develop selective mutism; a child with selective mutism can have sensory or social particularities that suggest autism. The differential diagnosis is made by a trained psychologist or psychiatrist, who assesses both dimensions. Management: cognitive behavioral therapy (CBT), gradual desensitization, sometimes occasional medication (SSRIs in older children), school support with accommodations (not forcing them to speak aloud, accepting writing and gestures). Often reversible with appropriate support.

Sources: DSM-5; child-anxiety guidelines; selective-mutism organizations.

Category 8 — Particular behaviors

Ten questions to understand meltdowns, stims, rituals, hypersensitivity, and the behaviors that worry parents.

Q71. Why does my child have meltdowns?

Meltdowns in an autistic child are not tantrums, but breakdowns due to overload. They occur when the child reaches a saturation threshold (sensory, emotional, cognitive, social) that they can no longer contain. Typical triggers: loud noise, bright light, crowds, fatigue, hunger, frustration, an unexpected change, silent pain (toothache, ear infection, constipation), information overload, social conflict, a difficult transition. During the meltdown, the child may scream, cry, hit, bang their head, self-injure, run away, or freeze. They are not able to listen, to reason, or sometimes even to recognize those around them. What to do: ensure safety (clear space, remove dangers), reduce stimulation (soft light, silence, few words), offer a refuge (a blanket, a cushion, an enclosed space), wait for the de-escalation (10 to 60 minutes). Do not reason, do not punish during the meltdown. AFTER the meltdown: a moment of repair, hydration, rest. Identify the triggers, anticipate, put strategies in place (breaks, noise-cancelling headphones, saturation signals). Professional advice is useful.

Sources: international clinical guidelines; Mazefsky et al. 2013; research-institute data 2023.

Q72. What is the difference between a meltdown and a tantrum?

Crucial, and too often confused. A tantrum is a voluntary behavior, directed toward a goal (getting something, escaping a constraint), often stops when it is not rewarded, can be negotiated, and presupposes awareness of its effect on others. A meltdown is an involuntary breakdown due to overload: the child no longer has control of their body or their emotions, is not trying to manipulate, has no goal, cannot negotiate, does not respond to rewards or punishments, and is themselves in great distress. The meltdown ends naturally through exhaustion, not by decision. Some signs: a meltdown often begins with signs of saturation (agitation, avoidant gaze, vocalizations, withdrawal), a tantrum begins in response to a specific refusal; the meltdown leaves the child exhausted and sad, the tantrum stops dead as soon as you give in. Autistic children can have both, but meltdowns dominate. Never punish a meltdown, never reward a tantrum. Learn to tell them apart — your parental perspective changes everything.

Sources: Lipsky D., Meltdowns 2008; international clinical guidelines.

Q73. What is a stim or a repetitive behavior?

Stimming (from self-stimulation) consists of repetitive behaviors that regulate sensations and emotions: flapping (hand movements), rocking, jumping, spinning, chewing, repetitive vocalizations, lining up objects, spinning objects, sideways glances, rubbing. They have essential functions: to calm down in a stressful situation, to stimulate in a boring environment, to express pleasure or intense joy (“happy flapping”), to concentrate, to manage an emotion that is hard to name. Stims are not pathological in themselves: everyone stims to some degree (tapping a foot, biting nails, chewing a pen). In autistic people, they are more visible, more frequent, more intense. Should they be stopped? Not as a general rule. What should be addressed: dangerous stims (self-injury, banging the head against the wall), and those that prevent learning or sociability (but we seek to replace them, not simply extinguish them). For the rest, stims are a useful form of regulation. Imposing sensory silence deprives the child of a self-regulation skill.

Sources: Kapp et al. 2019; international clinical guidelines; research-institute data 2023.

Q74. What is a restricted interest?

Restricted interests (sometimes called “specific interests” or “intense passions”) are one of the two main features of autism (along with social-communication difficulties). They consist of a very intense, exclusive, lasting focus on a specific area: dinosaurs, trains, planets, flags, numbers, TV series, anatomy, weather, mythological legends, video games, animals, birds, transport, a particular brand, a particular person. The child or adult can accumulate impressive expertise on their subject, talk about it for hours, refuse other conversations. Far from being an “obsession” to fight, restricted interests are today recognized as a potential asset to value: they are a source of well-being, identity, motivation, sometimes a lever for learning (learning to read thanks to dinosaur names), a future career (paleontology, transport, computing). What can be problematic: total exclusivity that prevents other activities, monologues that make interactions difficult. Strategy: do not extinguish it, but channel it (dedicated times, topics accepted in society, links with learning).

Sources: international clinical guidelines; Mottron L. 2011; Grove et al. 2018.

Q75. What is sensory hypersensitivity?

Sensory hypersensitivity is a feature present in 70–95% of autistic people according to studies (an official DSM-5 criterion since 2013). It can concern all the senses: hearing (unbearable harmless noises — hand dryers, vacuum cleaners, crowds, sirens), vision (fluorescent lights, fast movements, flickering), touch (clothing labels, seams, certain textures, unexpected contact), taste (refusal of most foods, extreme selectivity), smell (perfumes, disinfectants, certain foods), proprioception (body sense, balance). Consequences: sensory meltdowns, avoidance of places (supermarket, canteen, school), refusal of certain actions (toileting, washing, brushing), sleep disorders, chronic fatigue. Conversely, some autistic people are hyposensitive: they do not feel pain, seek strong sensations (jumping, pressure, rocking), do not react when called. Strategies: an occupational therapist specialized in sensory integration, noise-cancelling headphones, tinted glasses, adapted clothing, a weighted blanket, gradual desensitization. Adapt the environment before expecting the child to adapt.

Sources: DSM-5; Marco et al. 2011; international clinical guidelines.

Q76. My child eats only 3 foods — what can I do?

Food selectivity is very common in autistic children (60–70% of them, versus 25% of typical children). It can concern textures (refusing soft, accepting only crunchy), colors (only white, only beige), specific brands (only certain pasta, certain purée), temperatures, shapes. Consequences: nutritional risks (deficiencies in iron, calcium, vitamin

D, B12, zinc), weight gain or thinness, mealtime stress, social isolation. First steps: 1) check there is no medical cause (reflux, food allergy, digestive disorders, dental problems) — a pediatric assessment; 2) do not force (this makes it worse); 3) keep the accepted foods and introduce ONE new food at a time, over several weeks, starting with looking, smelling, touching (without eating); 4) an assessment by an occupational therapist specialized in feeding, sometimes a speech-therapy assessment; 5) dietitian follow-up for any supplements; 6) approaches such as oral education, the SOS Approach to Feeding, or feeding programs. Patience, a great deal of patience. Always in connection with your pediatrician.

Sources: Sharp et al. 2013; international clinical guidelines.

Q77. My child doesn't sleep — how can I help?

Sleep disorders affect 50 to 80% of autistic children (versus 25–40% of typical children). Difficulty falling asleep, night waking, very early waking, light sleep, night terrors, sleepwalking: anything is possible. Multiple causes: anxiety, sensory hypersensitivity (noise, light), rigidity (fear of the changing night, of dreams), digestive problems, unexpressed pain, melatonin-production anomalies. Strategies: 1) very structured visual routines (a posted evening sequence), fixed times; 2) an adapted bedroom (total darkness, silence, a temperature of 18–19°, sometimes white noise, sometimes a weighted blanket); 3) avoiding screens 1 hour before bed; 4) physical activity during the day; 5) avoiding hidden caffeine (chocolate, certain sodas); 6) if needed and after medical advice: prolonged-release melatonin (approved for autism in some regions) — very effective in about 60% of cases, at an adapted dose, on medical prescription. 7) A sleep study if the disorder is serious: polysomnography, screening for apnea. The advice of a pediatrician or child psychiatrist is always needed before any medication.

Sources: international clinical guidelines; melatonin marketing authorizations; Souders et al. 2017.

Q78. How do I manage transitions and changes?

Transitions (moving from one activity to another, going out, coming home, changing rooms, ending a game) and changes (of routine, environment, person) are among the major difficulties of autism. Rigidity, the need for predictability, attachment to routines are strategies the child develops to manage a world they perceive as chaotic and unpredictable. Effective strategies: 1) Anticipation: warn verbally and visually of changes in advance (5 minutes before, 1 minute before, now); 2) Visual supports: a daily schedule, activity sequences, visual timers (Time Timer), pictograms; 3) Use transition rituals: a rhyme, a transition object, a repeated routine; 4) Prepare important changes through social stories (Carol Gray) or videos; 5) Reduce surprises: warn of a schedule change, a substitute, a different route; 6) Keep some elements stable even within change (the same soft toy, the same outfit, the same song). With time and predictability, many children gain flexibility.

Sources: international clinical guidelines; Mesibov and Shea, TEACCH 2010; Gray C. 2010.

Q79. Self-injury and aggression toward others — what should I do?

Self-injurious behaviors (biting oneself, hitting oneself, scratching, pulling out hair) or aggression toward others (hitting, pinching, biting others) are among the most painful situations for families. They are never gratuitous: they communicate distress, pain, frustration, a lack of words, saturation. Approach: 1) RULE OUT A MEDICAL CAUSE first: dental pain, ear infection, constipation, reflux, headache, stomach ache, ENT or eye problems. Do a complete check-up. 2) Identify the triggers (an observation log: time, context, what precedes, what follows). 3) Give a way to communicate (PECS, signs, tablet) — many self-injurious behaviors disappear with communication. 4) Adapt the environment (reduce sensory overload, anticipate transitions). 5) Teach replacement behaviors (biting a chewy toy instead of oneself). 6) Involve a trained behavioral psychologist (ethical ABA, functional analysis). 7) Medical advice is imperative, sometimes occasional medication if there is danger (risperidone, aripiprazole — approved for autism). NEVER punish.

Sources: international clinical guidelines; Iwata et al. 1994; Carr and Durand 1985.

Q80. My adolescent child is becoming aggressive — is it linked to autism?

Adolescence is often a difficult period for young autistic people: hormonal changes, increased social expectations, heightened awareness of difference, bullying, anxiety, depression, sleep disorders, sometimes epilepsy that begins in adolescence (30% of autistic people are affected over the course of life). Aggression can be the expression of unspoken suffering. Before treating it as a “behavior problem,” you must look for: 1) a medical cause (pain, emerging epilepsy, hyperthyroidism); 2) an associated psychiatric disorder (depression, severe anxiety, bipolar disorder that can appear in adolescence, sometimes OCD); 3) an event (bullying, bereavement, separation, change); 4) an increased sensory difficulty (a changing body, hygiene, perspiration, clothing); 5) an accumulation of small unverbalized frustrations. Carry out a medical and psychiatric assessment, adjust the support, sometimes add a treatment (anti-anxiety, antidepressant, a second-generation antipsychotic as a last resort). Do not wait. Many autistic adolescents benefit from regular child-psychiatry follow-up at this time. Resources: specialist centers, associations.

Sources: international clinical guidelines; Simonoff et al. 2008; research-institute data 2023.

> Valentine’s reflection: “When my son had a meltdown, I wanted it to stop. Today I want to understand it first. That changed everything. The meltdown is not a problem: it’s a message.”

Category 9 — Family and social life

Ten questions about family life with autism: couple, siblings, grandparents, friends, holidays, respite.

Q81. How do I support the couple in the face of the diagnosis?

An autism diagnosis is a major ordeal for the couple. The separation rate of parents of autistic children is higher than average (Hartley et al. 2010; but nuanced by Freedman et al. 2012). Why? Chronic stress, exhaustion, disagreements over support choices, a sense of injustice, social isolation, the loss of the previous couple life, an asymmetric mental load (often carried by the mother). Protective strategies: 1) Acknowledge that it is hard — do not feel guilty for suffering; 2) Communicate regularly with each other about something other than the child (ban “100% autism” evenings); 3) Preserve time as a couple, even brief (1 hour a week without the child); 4) Share the steps fairly (paperwork, appointments, school); 5) Accept that each person grieves in their own way, at their own pace; 6) Ask for professional help: couple counselling, couple therapy, a parents’ support group; 7) Do not sweep your suffering under the rug. The couple is an essential partner for the child. Preserving it is also caring for the child.

Sources: Hartley et al., J Fam Psychol 2010; Freedman et al. 2012; autism associations.

Q82. How do I talk about autism to brothers and sisters?

The siblings of autistic children have a particular experience: strong love for their brother/sister, but also sometimes awkwardness, jealousy (parental attention is partly absorbed), fear, social shame, sometimes a self-assigned mission to “be the perfect child” so as not to overload the parents. Recommendations: 1) Talk simply and early (from 3–4 years): “your brother/sister has a brain that works differently, which makes some things hard, but it doesn’t change the love we have for them”; 2) Adapt over time: childhood (concrete descriptions), pre-adolescence (mechanisms, perspectives), adolescence (deeper exchanges); 3) Preserve individual moments with each child — 30 minutes a week of exclusivity change everything; 4) Allow siblings to express their emotions, including negative ones, without judgment; 5) Do not make them carry adult responsibilities (“you’ll have to look after them later”); 6) Connect them with other siblings through groups. 7) If needed, individual psychological follow-up. The siblings are a treasure to protect.

Sources: Tudor and Lerner 2015; autism associations, siblings.

Q83. What should I say to grandparents who don’t understand?

An autism diagnosis can be very hard for grandparents to accept, especially of an older generation: denial (“he’s just shy”), blame (“you let him get away with too much,” “it’s the vaccines,” “it’s the screens”), fear, sometimes shame, or conversely deep distress and a wish to help without knowing how. Strategies: 1) Give time — acceptance takes months, sometimes years. Do not demand immediate understanding; 2) Offer adapted resources: simple books, films, accounts by other grandparents (association forums); 3) Invite them to concrete moments (a meal, a short outing) rather than long theoretical explanations; 4) Give a concrete role (occasional childminding, material support, presence at follow-up meetings); 5) Maintain the bond despite disagreements; 6) Set limits if certain comments are hurtful (“I’d rather we didn’t say it’s our fault”). Some grandparents become the best allies. Some never will: it is sad, and it is OK.

Sources: autism associations; Hillman 2007.

Q84. How do I avoid social isolation as a parent?

The social isolation of parents of autistic children is massive: invitations dwindle (the child frightens, disturbs, makes noise), evenings with friends become complicated (who’s babysitting?), family outings are difficult (sensory issues, behaviors, stares), “ordinary” friends do not understand. Many parents describe a “bubble” closing in. Antidotes: 1) Join a community of peers: local associations (support groups), online groups, events (family cafés, autism days), conferences. Finding your group is the main source of oxygen. 2) Keep at least 2–3 reliable “ordinary” friends, to whom you genuinely explain, whom you don’t let go; 3) Bring the world in rather than going out (host at home, where the environment is under control); 4) Identify activities you can do WITH the child (swimming at off-peak hours, a walk in the forest, adapted sport, equine therapy); 5) Allow yourself moments without the child (relief: grandparents, specialized babysitting, temporary respite care); 6) Psychological support if exhausted.

Sources: autism associations; research-institute studies.

Q85. How do I avoid parental burnout?

Parental burnout very frequently affects parents of autistic children: a study by Mikolajczak and Roskam (2018) found a prevalence 3 to 5 times higher than among parents of typical children. The signs: emotional exhaustion, a feeling of ineffectiveness, emotional distance from the child (even though you love them), loss of parental pleasure, irritability, sleep disorders, depressive disorders. Causes: an enormous mental load (paperwork, appointments, school, care, supporting the child 24/7), a lack of respite, a deficit of recognition, isolation, grieving the expected child, anxiety about the future. Strategies: 1) Ask for help BEFORE collapse, not after; 2) Activate every form of relief (extended school support if possible, home-based support services, day care, specialized babysitting, adapted holidays); 3) Identify non-negotiable weekly respite times (a minimum of 10% of the time for yourself); 4) Individual psychological follow-up (a psychologist trained in the parenting of autism — not all are); 5) Occasional medication if depression is established (medical advice); 6) A parents’ support group; 7) Adapted holidays. You are your child’s engine: take care of yourself.

Sources: Mikolajczak and Roskam 2018; research-institute data 2023; autism associations.

Q86. How do I explain autism to school and social circles?

Not always easy: between the person who knows nothing, the one who thinks they know, and the one who asks intrusive questions. A few approaches depending on the audience: 1) School (teacher, support worker): a factual presentation, a welcome sheet (1–2 pages with: the child’s strengths, difficulties, strategies that work, strategies to avoid, a quick contact). Invite them to get trained (conferences, resources); 2) Extended family: personal accounts, anecdotes, books and films. Favor the concrete; 3) Friends:

transparency about what you are going through, without hiding the difficulty or dramatizing. Invite to a neutral event; 4) Strangers in public (checkout, restaurant, public place) who judge a meltdown: an "autism" card in your wallet (to hand over silently), prepared responses ("my child is autistic, thank you for your understanding"); 5) Doctors, dentists, administrative services: a briefing beforehand, visual supports, a pre-visit if possible. Overall: choose your battles, do not explain everything to everyone, keep some energy. No one will understand 100%. And that is OK.

Sources: autism associations; resource centers.

Q87. My child and I are invited somewhere — how do I manage?

Social invitations (birthdays, weddings, family parties, restaurants) are often stressful moments. Possible preparation: 1) Assess beforehand whether the outing is feasible (duration, venue, noise level, possible transition to a quiet space); 2) Prepare the child: photos of the place, a visual program, a social story ("there will be lots of people, cakes, candles, songs, it will be noisy…"); 3) Prepare a survival bag: noise-cancelling headphones, a comfort toy, a tablet/game as a refuge, familiar snacks, water; 4) Have a fallback plan (a quiet room, a garden, the car as a refuge); 5) Warn the host ("we might come for just 1 hour," "we might have to leave quickly"); 6) Choose your timing (arrive before the sensory rush hour); 7) Do not feel guilty about leaving early or declining an invitation — your limits are a form of care. Tip: invitation by invitation, the child can tolerate more and more, provided their limits are respected. Gradual desensitization works. Absolute forcing breaks things.

Sources: autism associations; parental practice.

Q88. How do I go on holiday with an autistic child?

Holidays are both necessary and dreaded. Tips: 1) Choose the destination according to the child (a calm place, not too crowded, the possibility of swimming, close to home), not according to classic tourist criteria; 2) Favor furnished rentals (holiday cottages, apartments) rather than hotels (private space, a familiar kitchen, privacy); 3) Keep reference points: a comfort toy, favorite toys, a familiar cereal brand, the home's bedding, the usual evening routine; 4) Prepare in advance: photos of the accommodation, the journey, the activities; a visual program of the days; 5) Keep a familiar rhythm (meal and bedtimes); 6) Anticipate transport: if flying, request disability assistance; if by train, an adapted seat; if by car, frequent breaks; 7) Know the local emergency services (specialist centers, pediatric emergencies) before leaving; 8) Adapted solutions: holidays with associations, adapted holiday centers, sibling stays. Successful holidays = adjusted holidays, not "normal" holidays.

Sources: autism associations; adapted-holiday organizations.

Q89. Are there respite solutions for parents?

Yes, but they are still largely insufficient. A few options: 1) Temporary care in a specialized establishment: a few days or weeks per year, for the child, with an orientation from the disability authority; 2) Respite services: home help, specialized babysitting, respite days; 3) Adapted holiday centers (run by associations): stays of one to two weeks with trained supervision; 4) Specialized foster families (few in number — ask your local social services); 5) Specialized babysitting: associations that train students in psychology/education to look after autistic children; 6) Home care by trained practitioners (sometimes fundable through disability-compensation benefits); 7) Weekly boarding in a specialized establishment for older children. Approach your social services, your local disability department, your national autism association. Do not feel guilty about asking: respite is care for the whole family.

Sources: national disability agencies 2024; national autism strategies; autism associations.

Q90. How do I prepare my child for a major change (moving, divorce)?

Major changes (moving, divorce, the birth of a sibling, bereavement) are ordeals for any child — magnified for an autistic child, whose rigidity and need for predictability are structural. Strategies: 1) Announce the change EARLY, but not too early (neither “we’re moving tomorrow” nor “in 6 months”) — 2 to 4 weeks ahead depending on the child; 2) Use visual supports: photos of the new home, a plan of the new bedroom, social stories (Carol Gray), a visual calendar of the move with dated steps; 3) Preserve as many reference points as possible: the same bedroom organized identically, the same soft toys, the same habits, the same school if possible; 4) Visit, redo the route, take photos to anticipate; 5) In case of divorce: keep both parents present, a visualized custody calendar, photos of each home, a comfort toy that travels between them; 6) Allow the expression of emotions (drawing, writing, modelling with figurines); 7) Psychological support if needed. Patience: behavioral regression after a big change is normal and temporary (a few weeks to a few months).

Sources: Gray C., social stories 2010; international clinical guidelines.

> Valentine’s reflection: “Isolation is what hurt me the most. The day I found other mothers living through the same thing, I started to breathe again. Look for your tribe. It exists.”

Category 10 — The future

Ten questions about what awaits your child in adolescence, adulthood and beyond: autonomy, working life, emotional life, housing.

Q91. Will my autistic child be able to live alone one day?

A legitimate question that haunts every parent. The honest answer: it depends enormously on the individual profile. Across all autistic adults, the studies (Howlin 2013, Roux et al. 2015) show great variability: about 20 to 25% live in complete autonomy (living alone or as a couple, in mainstream employment), 30–40% in partial autonomy (living alone or in shared housing, with support), 30–40% in supported housing (a residential home, a care home) or with their parents. The favorable factors: quality early intervention, preserved IQ, functional language, adapted schooling, continuous family support, treated comorbidities (anxiety, epilepsy), the learning of daily-living skills from childhood (cooking, getting around, managing money, managing emotions), the prospect of adapted employment. Work on functional skills as much as academic learning from childhood. Inclusive housing: new forms of housing (supported shared living, inclusive living homes, supported flats) are developing. Prepare for the future, without presuming it.

Sources: Howlin et al., Lancet 2013; Roux et al. 2015; national disability agencies 2024.

Q92. What should I do in adolescence when everything gets complicated?

Adolescence is often a difficult period for young autistic people: heightened awareness of difference, a desire for social relationships but persistent difficulties, bullying, social anxiety, depressive disorders, suicidal ideation (a risk 7x higher than in the general population — Hirvikoski et al. 2016), sometimes the onset of psychiatric disorders (OCD, anxiety disorders, depression, sometimes epilepsy). Strategies: 1) Maintain regular medical and psychological follow-up (psychologist, psychiatrist, primary care doctor) — adolescence is not the time to stop care; 2) Support identity (peer groups of autistic adolescents, adult role models), allow self-regulation (specific interests, personal space); 3) Anticipate transitions (orientation, sexual life, autonomy) with adapted programs; 4) Watch for warning signs (withdrawal, self-harm, suicidal statements, massive school refusal, risk-taking, substance use) and seek urgent help if needed (your local emergency number, a suicide-prevention helpline — findahelpline.com); 5) Work on social skills in a group, on sex education, on substance awareness, on emotions. Do not stay alone. Adolescence is better crossed with others.

Sources: Hirvikoski et al. 2016; international clinical guidelines.

Q93. How do I prepare for everyday autonomy?

Autonomy is a long road that begins in childhood. The skills to work on: 1) Hygiene: washing, brushing teeth, dressing (with visual sequences), managing periods in adolescence; 2) Meals: choosing, simple cooking, doing the shopping (a visual list), managing a food budget; 3) Money: the value of coins, shopping, paying, managing an account; 4) Mobility: the home-to-school journey alone, public transport (with visual apps like Citymapper, Moovit), cycling, sometimes a driving licence; 5) Communication: phoning, writing an email, asking for help, managing an appointment; 6) Domestic: tidying the bedroom, making the bed, laundry, basic cleaning; 7) Safety: recognizing dangers, asking for help, knowing how to say no. Method: breaking down into small steps, visual supports (TEACCH), repeated practice, generalization across several contexts. An occupational therapist specialized in daily autonomy can help. Social-support services intervene with young adults. Patience and consistency.

Sources: international clinical guidelines; national disability agencies 2024.

Q94. What jobs are possible for an autistic person?

All jobs are theoretically possible, and many autistic adults have remarkable careers. It all depends on the profile. The best-known profile: autistic people with preserved IQ often excel in fields that value concentration, precision, logical thinking, systematization: computing (programming, cybersecurity, software testing, data), sciences (research, mathematics, physics, engineering), accounting, archiving, visual arts (illustration, photography), technical trades (mechanics, watchmaking, electronics), animals (veterinary work, animal care, naturalism), libraries, music. Difficulties encountered: the social interactions of work, job interviews, sensorially difficult open-plan offices, implicit hierarchy, informal communication. Solutions: employment recognition, remote work, adapted positions, a company whose culture values neurodiversity (several large companies have autism programs), sheltered workshops for profiles with an associated disability, adapted enterprises. Resources: specialized employment services, employment-support agencies, neurodiversity-at-work associations. Employment is possible — it often requires an adapted environment.

Sources: Roux et al. 2015; employment-support agencies.

Q95. Can an autistic person be in a relationship, marry, have children?

Yes, absolutely. Autistic people have the same emotional and sexual needs as everyone else. Many live as a couple (with or without a diagnosis of the partner, who may also be autistic — autistic couples are not rare), marry, have children, and are committed, loving parents. Possible particularities: difficulty expressing emotions verbally, a need for routine and personal space, hypersensitivities to manage (touch, noise, intimacy), sometimes direct or literal communication (“I love you, I’ve said it, I’m not going to repeat it every day”), the need for a partner who understands and respects these particularities. A few tips: sex education adapted in adolescence (books, association resources); explicit communication within the couple (do not expect the other to guess); help in case of difficulty (couple therapy with a psychologist trained in ASD). In case of parenthood, support is useful (maternal and child health services, a psychologist), because parental sensory issues can be delicate (crying, physical contact). An emotional and romantic life is a right.

Sources: international clinical guidelines; autism-and-sexuality resources; Hendrickx 2015.

Q96. The transition to adulthood: what changes administratively?

At 18, several important administrative changes occur: 1) A child education allowance becomes an adult disability allowance — the request should be made 6 months before coming of age; 2) Employment recognition is possible if there is a professional plan; 3) Adult disability-compensation benefits (same principles); 4) A school support worker no longer exists, replaced by possible support in higher education (a university disability office, a student disability allowance) or in vocational training; 5) An adult mobility/inclusion card; 6) A possible legal-protection measure (family authorization, assisted decision-making, guardianship) if management autonomy is insufficient — handled through the court with a medical certificate from an approved physician; 7) A recommended adult health check (transition from pediatrician to a primary care doctor); 8) Registration with employment services if seeking work; 9) Affiliation to the relevant health-insurance scheme. Anticipate: begin the steps 6 to 12 months before the 18th birthday. Specialist centers, a social worker and associations are precious resources for this transition.

Sources: national disability agencies 2024; disability authorities.

Q97. What are sheltered workshops and adapted enterprises?

Two arrangements for employment in a protected setting. A sheltered workshop takes in workers recognized as having a disability (through an orientation from the disability authority) who cannot work in a mainstream setting. It offers a professional activity (packaging, subcontracting, catering, green spaces, cooking) with specialized supervision and medico-social support. Pay is often a percentage of the minimum wage depending on the activity, and can be combined with an adult disability allowance. The status is particular: not really an employee, not really a service user. Places are insufficient. An adapted enterprise, by contrast, is a real mainstream-sector company that employs at least a majority of workers with disabilities. Minimum-wage salary, a real employment contract. Very varied production (industry, services, digital). To join a sheltered workshop: an orientation from the disability authority, a direct application, an observation period. For an adapted enterprise: a classic application (CV, letter, interview), with employment recognition appreciated. Specialized employment services provide support.

Sources: national disability agencies 2024; employment-support agencies.

Q98. What housing solutions are there for an autistic adult?

Several options depending on the degree of autonomy. 1) The parental home: still largely the majority among young autistic adults (parental exhaustion to anticipate). 2) Ordinary individual housing with support from a social-and-medico-social service: help with daily life, paperwork, social life, care. 3) Inclusive housing (growing): shared living between people with disabilities with help for communal life, in private or social housing. Shared-living support can be funded. 4) A residential home: for sheltered-workshop workers, collective accommodation with supervision in the evening and at weekends. 5) A living home: for adults without a professional activity, with permanent support. 6) A medicalized care home: for adults needing significant medical care. 7) A specialized care home: for heavily dependent adults. An orientation from the disability authority is needed for all these arrangements. Waiting lists can be long (1–5 years depending on the region). Anticipate from age 16–18.

Sources: national disability agencies 2024; disability authorities.

Q99. Will my child be able to pursue higher education?

Yes, many autistic adults have pursued and are pursuing higher education, sometimes up to doctorate level. What helps: 1) Accommodations in upper-secondary and then higher education (extra time, a scribe, a computer, isolated rooms, written supports, exemption from certain oral exams) — request these from the disability offices of universities/colleges; 2) Choice of course: favor fields that match the student's interests and skills; 3) Adapted settings: universities with active disability offices have excellent arrangements; networks dedicated to autistic students in higher education provide training and support; 4) Student life: adapted housing (a disability-allocated room, social housing, shared living), medical and psychological follow-up, accommodations for meals (cafeterias can be sensorially difficult); 5) Anticipation of transitions and of the move from studies to employment (student employment services, work-study schemes, a first supported job). Higher education = as accessible as average, provided there are accommodations. Resources: higher-education disability services.

Sources: higher-education disability networks; university disability offices.

Q100. What message of hope would you give to parents at the start of the journey?

The announcement of the diagnosis is a shock. Many parents remember the day, the sentence, the doctor's look. And what follows is often a fog: paperwork, waiting, methods, doubts, fatigue. Yet this journey, seen from a distance, tells another story. First: no parent is alone. You will meet other parents, professionals, associations, who form a real community. Second: your child is not a file. Beyond the difficulties, this is a child who loves, who laughs, who attaches, who learns, who surprises. Third: what you do matters. Every hour of presence, every game, every repeated word, every meltdown weathered, every successful outing is a brick in the life being built. Fourth: there is no age limit for making progress. Many children astonish at 7, at 12, at 18. The trajectory is never linear. Fifth: take care of yourself too. The child needs a living parent, not an exhausted one. Be patient with them, and with yourself. And never forget: you are the expert on your child. Trust yourself.

Sources: personal accounts; autism associations; sortirdelautisme.fr resources.

> Valentine's reflection: "When the diagnosis was announced to me, I thought the future was collapsing. Today, I know that the future is written differently — and that it can be beautiful. Different, but beautiful."

Going further

Useful contacts

- Your national autism association — for information, guidance, and local support
- Your primary care doctor or pediatrician — the first point of contact for any concern
- Your local emergency number — for any immediate medical or safety emergency
- A suicide-prevention helpline — find the one for your country at findahelpline.com
- A national child-protection or parenting helpline, where one exists in your country

Reference resources

- The World Health Organization (WHO): who.int
- The CDC's autism information and milestone trackers: cdc.gov
- Your national autism association and its regional networks
- International research institutes and the published clinical guidelines cited throughout this guide

Valentine's book

Breaking the Codes — a personal account and a resource for families. Available via sortirdelautisme.fr

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FAQ — 100 Questions About Autism — sortirdelautisme.fr — Valentine Lecêtre — 2026