



FAMILY & CAREGIVER AUTISM TOOLKIT

A Practical Evidence-Informed Guide for Understanding, Supporting and Planning Across Home,
Health, Education and Community Life



Edition 1.0 | September 2026

Global Autism Research Center (GARC)

globalautismresearch.org.uk



Publication Information

Purpose and scope

This toolkit is designed for parents, family members, guardians, kinship or foster carers, and other trusted caregivers supporting an autistic child, young person or adult. It translates evidence-informed principles into practical actions for everyday life. It is intentionally broad and lifespan-oriented because support needs, family roles and local service systems vary widely.

Clinical and legal notice

This publication is educational and is not a substitute for individualized medical, psychological, educational, legal or social-care advice. Autism does not have one universal support plan. Decisions about health, medication, nutrition, mental health, safeguarding, education and legal arrangements should be made with appropriately qualified professionals and, wherever possible, with the autistic person actively involved. In an immediate emergency or risk of serious harm, use local emergency or crisis services.

Language and dignity

This toolkit generally uses identity-first language ("autistic person") while recognizing that preferences differ. Ask the individual and family what language they prefer. Avoid language that reduces a person to deficits, assumes incapacity, or treats harmless autistic traits as problems simply because they look different.

Evidence approach

The guidance draws primarily on international and national public-health guidance and clinical practice recommendations, including the World Health Organization (WHO), the U.S. Centers for Disease Control and Prevention (CDC), the U.S. National Institute of Mental Health (NIMH), the National Institute for Health and Care Excellence (NICE), and the American Academy of Pediatrics (AAP). Sources are listed at the end of the toolkit. Guidance is interpreted for practical family use rather than copied from source publications.

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REVIEW CYCLE

GARC intends to review this toolkit periodically and earlier if major evidence or authoritative guidance changes. Users should always verify current local requirements and service pathways.



Foreword

Families often encounter autism through a sequence of questions rather than a single moment: Why is communication difficult today? Why did a routine change lead to distress? Which supports matter most? Which professional should we contact? What should we ignore? How do we plan for school, health, relationships, adulthood and independence without losing sight of the person in front of us?

The most useful family support is neither a race to normalize behaviour nor a collection of disconnected therapies. It is a coordinated way of understanding the person, removing avoidable barriers, teaching useful skills, protecting health and safety, and preserving dignity, autonomy, connection and quality of life.

This toolkit is designed to help families turn uncertainty into a practical system. It offers a common language, a family support framework, evidence-aware decision tools, role-specific guidance and reusable templates. It does not assume that every autistic person wants the same goals or uses the same communication. It starts from the opposite premise: support should be individualized, respectful, measurable and shaped by the person's needs, strengths and preferences.

Global Autism Research Center (GARC)

Practical Toolkits Series



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HOW TO USE THIS TOOLKIT

Do not try to implement everything at once. Start with the Quick Start section, identify two or three high-priority needs, select the relevant sections, and use the templates to create a shared plan with the autistic person and the people who support them.



Quick Start: The First 30 Days

If a diagnosis is new - or you are still seeking answers

A diagnosis can bring relief, uncertainty, grief, validation, practical questions, or several of these at once. There is no required emotional response and no need to make every decision immediately. A useful first month is about understanding the person, collecting reliable information and building a small, coordinated support map.

- ☐ Ask for a copy of the assessment or diagnostic report and write down questions for the follow-up appointment.
- ☐ Identify the person's most immediate priorities: communication, sleep, school access, pain, safety, distress, daily living, relationships or something else.
- ☐ Create a one-page support profile that records communication, strengths, sensory needs, distress signs, helpful strategies and important health information.
- ☐ Contact the relevant local education, early intervention, disability or adult-support pathway; eligibility and processes vary by jurisdiction.
- ☐ Book or maintain routine primary healthcare and raise specific concerns such as sleep, feeding, constipation, seizures, pain, anxiety, attention or mood.
- ☐ Choose one communication-support strategy and one predictability strategy to use consistently at home.
- ☐ Review immediate safety risks: wandering, traffic, water, fire, medication, online safety, self-injury, exploitation or other context-specific risks.
- ☐ Identify at least one person who can provide practical or emotional support to the main caregiver.
- ☐ Keep a simple log of what helps, what increases distress and what changes over time.
- ☐ Avoid high-pressure promises, expensive packages, or claims that autism can be "cured" quickly. Ask for evidence, risks, costs and measurable goals before committing.

URGENT HELP

Seek urgent local medical or emergency help if there is immediate danger, serious injury, suspected abuse, sudden major loss of skills, a first or prolonged seizure, severe dehydration, breathing difficulty, poisoning/overdose, or credible risk of suicide or serious self-harm. This list is not exhaustive.



Quick Start: One-Page Family Priorities

Use this page before appointments or team meetings. The goal is to move from a long list of concerns to a small number of shared priorities.

Priority	What is happening now?	What would “better” look like?
1		
2		
3		
4		

What already works

- ☐ Communication methods that work: _____
- ☐ Calming/regulation supports that work: _____
- ☐ Interests, strengths and motivators: _____
- ☐ People or places that feel safe: _____

The next meeting should answer

- ☐ What is the goal?
- ☐ How will progress be measured?
- ☐ Who is responsible for each action?
- ☐ What will happen at home?
- ☐ What will happen at school/work/healthcare?
- ☐ When will we review and change the plan if it is not helping?



SECTION 1

Understanding Autism in Everyday Family Life

A practical foundation for seeing the whole person: strengths, differences, disability, context and support needs.

- Understand autism as a diverse neurodevelopmental condition, not a single presentation.
- Separate observable behaviour from assumptions about intention or motivation.
- Expect needs and abilities to change across environments and life stages.

GARC PRACTICE PRINCIPLE

The goal of support is not to make an autistic person appear less autistic. It is to improve access, communication, wellbeing, participation, safety and self-determination.

1.1 Autism is a spectrum of profiles

Autism is a diverse group of conditions related to brain development. Characteristics commonly involve differences in social communication and interaction, patterns of interests or activities, transitions and sensory responses. Abilities and support needs vary widely and may change over time. [1,3]

Area	Possible everyday impact
Communication	The person may use speech, AAC, gestures, writing, typing, signs or a combination. Fluent speech does not automatically mean easy comprehension, emotional regulation or self-advocacy.
Social connection	The person may prefer different forms, intensity or timing of social interaction. Difficulty reading implied meanings is not the same as lack of care or interest.
Predictability	Unexpected changes, unclear sequences and open-ended demands can increase cognitive and emotional load.
Sensory processing	Sound, light, touch, smell, taste, temperature, movement, internal body signals or pain may be experienced differently.
Interests and repetition	Focused interests and repetitive movement may support joy, learning, predictability and regulation.
Executive functioning	Starting, stopping, switching, planning, sequencing and estimating time may require explicit external supports.
Co-occurring needs	Autistic people may also experience ADHD, anxiety, sleep disturbance, epilepsy, feeding difficulties, gastrointestinal problems, learning disability or other health needs. [5,7]

1.2 Strengths-based does not mean needs-blind

Families often hear either deficit-only descriptions or overly positive messages that make disability disappear. A useful approach holds both truths: an autistic person can have meaningful strengths and still



need substantial support. Strengths might include deep knowledge, persistence, honesty, creativity, visual reasoning, pattern recognition, memory, attention to detail, loyalty or distinctive problem solving. The right question is not “high functioning or low functioning?” but “What can this person do, what is difficult, and what support changes the outcome?”

DO

Describe specific skills and support needs. Ask what helps the person understand, recover, participate and make choices.

AVOID

Using broad functioning labels as substitutes for planning, or assuming competence in one area means independence in every area.

1.3 Behaviour is information - but not always a message

Some behaviour is a response to demands, pain, sensory overload, communication difficulty, fatigue, fear, uncertainty or loss of control. Some behaviour is simply self-expression or regulation. Before trying to stop a behaviour, ask whether it is harmful, what may be contributing to it, and whether the environment can change. NICE recommends assessing communication, physical health, mental health, environment, routine changes and other factors when distress-related behaviour increases. [4]

Ask first	Why it matters
Is there pain, illness, hunger, constipation, dental discomfort or sleep loss?	Physical problems may be expressed through behaviour, especially when pain is hard to describe.
Did something change?	New people, routes, schedules, expectations or loss of a familiar activity can increase uncertainty.
Is communication working?	The person may need a faster or more reliable way to request “stop”, “help”, “break”, “finished”, “pain” or “no”.
Is the environment overwhelming?	Noise, light, touch, crowding, smell or social pressure can accumulate.
What happened before and after?	Patterns are easier to see when families record context rather than only the behaviour itself.



SECTION 2

The GARC 10-Point Family Support Framework

A whole-family model for turning fragmented advice into coordinated, person-centred support.

- Use the framework to organize priorities across home, health, education and community life.
- Build supports around the autistic person, not around service boundaries.
- Review goals with the person and family rather than assuming yesterday's plan still fits.

GARC PRACTICE PRINCIPLE

Good support is understandable, coordinated and sustainable. If a plan only works when one exceptional caregiver is present, it is not yet a reliable system.

2.1 The framework

#	Domain	What “good” looks like
1	Know the person	Strengths, preferences, identity, goals, health, daily rhythms and what matters to them.
2	Communication access	Reliable ways to understand, express needs, refuse, ask for help and participate in decisions.
3	Regulation and sensory fit	Reduce avoidable overload and build predictable recovery options.
4	Health and pain	Treat health concerns seriously; do not attribute every change to autism.
5	Daily living and independence	Teach useful skills in small steps while preserving needed support.
6	Learning and service coordination	Align home, education, health and other supports around shared outcomes.
7	Relationships and belonging	Protect connection, friendship, family participation and community access.
8	Safety and safeguarding	Plan for real risks without unnecessarily restricting autonomy.
9	Family sustainability	Support caregiver wellbeing, siblings, respite, shared responsibility and emergency backup.
10	Future planning and self-determination	Prepare early for adolescence, adulthood, employment, living arrangements and decision-making.

2.2 A simple review question for every domain

FAMILY REVIEW

What is working? What is hard? What matters most now? What barrier can we remove? What skill or support would make daily life easier? Who owns the next action? How will we know whether it helped?



2.3 The minimum viable family plan

- ☐ One-page support profile
- ☐ Current health and medication list
- ☐ Communication method and emergency communication
- ☐ Sensory/regulation plan
- ☐ Top three family priorities
- ☐ Education/work support contact
- ☐ Safety plan for relevant risks
- ☐ Emergency and backup caregiver information
- ☐ Review date and named coordinator



SECTION 3

Communication, Connection and Self-Advocacy

Support communication as a right and a practical life skill - across speech, AAC, gesture, writing, visuals and behaviour.

- Use the person's most effective communication mode, not the most socially typical one.
- Increase opportunities to request, refuse, ask for help, share interests and make choices.
- Give processing time and reduce unnecessary verbal load.

GARC PRACTICE PRINCIPLE

Communication support should expand autonomy. A person needs a reliable way to say yes, no, stop, help, break, pain, finished and more - especially in stressful situations.

3.1 Start with communication function

Communication is more than speech. The practical goal is mutual understanding. Autistic people may communicate through speech, sign, gesture, body movement, pictures, symbols, communication boards, speech-generating devices, text or typing. Families should coordinate with appropriately qualified communication professionals when assessment or AAC support is needed.

Purpose	Examples of family support
Request	Keep preferred items or activities visible and provide an easy way to ask.
Refuse	Teach and respect “no”, “stop”, “not now” and “finished” whenever safety allows.
Ask for help	Make “help” quick to access before a situation becomes overwhelming.
Share/Comment	Respond to interests and observations, not only requests or questions.
Understand	Use short language, written or visual supports, demonstrations and predictable sequences.
Repair misunderstandings	Offer alternatives: “Show me”, “Point”, “Type it”, “Do you mean A or B?”

3.2 Reduce the “communication tax” at home

- ☐ Ask one question at a time.
- ☐ Pause after speaking; do not immediately repeat or rephrase.
- ☐ Use concrete language when ambiguity creates difficulty.
- ☐ Show the plan visually when several steps are involved.
- ☐ Avoid requiring eye contact to prove attention.
- ☐ Do not force speech when another reliable communication method is available.
- ☐ Make important choices real, limited and understandable.



3.3 Build a communication passport

Prompt	Record
I communicate best by...	
When I am calm, you may notice...	
My early signs of stress are...	
Please do this when I need more time...	
Ways I say “no/stop”...	
Ways I say “help/break”...	
Do not assume that...	

3.4 Self-advocacy begins with small choices

Self-advocacy is built through repeated experiences of being heard. Offer age- and ability-appropriate opportunities to choose, refuse, ask questions, request accommodations, describe discomfort and participate in planning. For adults, involve the autistic person directly in decisions and respect privacy; family involvement should match the person’s wishes and applicable law. NICE emphasizes partnership, accessible information and active participation in care decisions. [6]



SECTION 4

Sensory Regulation and the Home Environment

Design the environment so that regulation does not depend on constant self-control.

- Identify patterns in sensory load rather than labeling reactions as “overreactions”.
- Provide predictable low-stimulation options before distress escalates.
- Individualize sensory support; what helps one person may overwhelm another.

GARC PRACTICE PRINCIPLE

A sensory-supportive home is not necessarily silent or highly controlled. It gives the person predictable options, clear exits and ways to recover.

4.1 Build a sensory map

Sense / input	Possible signs of overload or seeking	Potential adjustments
Sound	Covering ears, leaving, humming, seeking loud sounds	Quiet zone, headphones/ear defenders when appropriate, warning before appliances, lower simultaneous sound
Light/visual	Squinting, avoiding bright rooms, fascination with visual patterns	Dimmable light, natural light, sunglasses where safe, reduce visual clutter
Touch/clothing	Avoids certain fabrics/touch or seeks pressure	Tag-free options, choice of fabrics, consent before touch, preferred pressure activities if safe
Smell/taste	Avoids rooms/foods or strongly seeks smells/flavours	Ventilation, unscented products, separate food smells, avoid forcing exposure
Movement/body	Pacing, rocking, jumping, crashing, avoiding movement	Safe movement opportunities, predictable breaks, appropriate seating options
Internal signals	Difficulty noticing hunger, thirst, toilet needs, fatigue or pain	Scheduled check-ins, visual prompts, hydration routine, symptom tracking

4.2 Create a regulation menu

Instead of one “calming strategy,” create several options and observe which work under different conditions. Regulation supports should be offered, not imposed, unless immediate safety requires intervention.

When I need...	Possible options to test
Less input	Quiet room, lower light, fewer people, headphones, closed door, reduced talking
More body input	Movement break, stretching, carrying safe objects, walk, rocking, preferred repetitive movement
More predictability	Visual countdown, written sequence, timer, preview of change, “first/then” plan



When I need...	Possible options to test
Less social demand	Parallel activity, reduced questioning, written communication, private recovery time
A familiar anchor	Preferred object, music, topic, routine, person, phrase or visual

4.3 Do not confuse regulation with compliance

A person who looks still may not be regulated, and a person who rocks, paces or repeats sounds may be regulating effectively. Intervene in repetitive or sensory behaviour when it is unsafe, painful, severely disruptive to the person's own goals, or clearly signals distress - not simply because it appears unusual.



SECTION 5

Daily Routines, Transitions and Growing Independence

Make everyday life more predictable while building useful skills without removing necessary support.

- Break routines into visible steps and teach one step at a time.
- Use prompts that can be gradually reduced rather than doing everything for the person.
- Define independence as “the right level of support,” not doing everything alone.

GARC PRACTICE PRINCIPLE

The best independence goal is meaningful to the person and family, safe enough to practise, and specific enough to teach and measure.

5.1 Why transitions can be hard

Transitions may combine several demands at once: stopping a preferred activity, shifting attention, predicting what comes next, tolerating uncertainty, organizing belongings and regulating sensory or emotional responses. Support the sequence rather than treating transition difficulty as deliberate opposition.

5.2 The transition ladder

1. Preview the change before it happens.
2. Show what is ending and what is next.
3. Give one or two concrete preparation steps.
4. Use a consistent cue such as a timer, visual countdown or phrase.
5. Allow a small completion ritual where possible.
6. Move to the next activity with minimal extra language.
7. After difficult transitions, review what to adjust next time.

5.3 Teaching daily living skills

Skill	Break it down	Support options
Getting dressed	Choose clothes → orient clothing → put on → fasten → check comfort	Picture sequence, laid-out clothes, adaptive fasteners, reduced choices
Hygiene	Prepare items → complete steps → rinse/dry → put away	Visual routine, sensory-friendly products, timer, modelling
Meal preparation	Select simple item → gather → prepare → clean	Written steps, pre-measured ingredients, safety adaptations
Travel	Route → timing → ticket/payment → safety → backup plan	Practice runs, maps, phone reminders, travel card, support person



Skill	Break it down	Support options
Money	Recognize amount → choose → pay → check change/balance	Budget app, visual spending categories, supported practice

5.4 Prompting without creating unnecessary dependence

PROMPT HIERARCHY

Use the least intrusive prompt that works: environmental cue → visual cue → gesture → brief verbal cue → modelling → physical guidance only when appropriate, consented and safe. Review whether prompts can be faded over time.



SECTION 6

Education and Learning Partnership

Create a practical bridge between home and school, college, training or other learning environments.

- Share information that helps participation, not private detail that staff do not need.
- Keep goals observable and connected to access, learning, communication and wellbeing.
- Use regular review rather than waiting for a crisis.

GARC PRACTICE PRINCIPLE

Families and educators see different parts of the same person. A useful partnership compares patterns across settings and agrees on a small number of shared supports.

6.1 What families should bring to education meetings

- ☐ A one-page student support profile
- ☐ Current strengths and interests
- ☐ Communication method and access needs
- ☐ Known sensory triggers and effective regulation options
- ☐ Health information relevant to school
- ☐ Examples of what helps learning and what blocks learning
- ☐ Top three priorities for the next review period
- ☐ Questions about attendance, participation, bullying, transitions and progress

6.2 Ask for observable goals

STRONGER GOAL	WEAKER GOAL
"With a visual schedule and one reminder, Sam will transition from preferred activity to homework within 5 minutes on 4 of 5 weekdays."	"Sam will improve behaviour and become more flexible."

6.3 Home-school communication that is sustainable

What to share	What to avoid
Changes likely to affect the day: poor sleep, new medication, major transition, acute illness	Long daily narratives that no one has time to use
What strategy worked and under what conditions	"It worked" without describing what was different
Patterns across several days or weeks	Interpreting one difficult day as a permanent regression
The student's own view where possible	Speaking about the student as if they are not part of the team



6.4 Bullying, exclusion and belonging

Families should take repeated exclusion, teasing, coercion, online harassment or unexplained school avoidance seriously. Ask where incidents occur, who is present, whether unstructured times are risk points, and what specific supervision or inclusion changes will be made. Do not rely only on telling the autistic person to “ignore it” or change their social style.



SECTION 7

Health, Sleep, Feeding and Co-Occurring Needs

Protect physical and mental health by treating new symptoms as health information - not automatically as “autism behaviour.”

- Maintain ordinary preventive healthcare and dental care alongside autism-specific supports.
- Prepare for appointments to make communication and sensory access easier.
- Escalate meaningful changes in sleep, eating, pain, seizures, mood or function.

GARC PRACTICE PRINCIPLE

Diagnostic overshadowing is a practical risk: a change in behaviour can reflect pain, illness, medication effects or mental health. Ask “what else could be happening?”

7.1 A family health baseline

Track	Why it helps
Sleep pattern	Changes in falling asleep, waking, duration and daytime fatigue can affect function and may need clinical review.
Eating and hydration	Restricted intake, weight change, choking, dehydration, constipation or nutrient concerns need appropriate assessment.
Bowel and bladder	Constipation, pain, accidents or change in pattern can contribute to distress.
Seizures or unusual episodes	Record timing, duration, context and recovery; seek clinical assessment.
Pain and physical symptoms	Look for changes in movement, posture, eating, sleep, self-injury, avoidance or facial expression when verbal reporting is difficult.
Mood and anxiety	Withdrawal, increased avoidance, panic, irritability, sleep change or loss of interest may warrant mental-health assessment.
Medication and supplements	Keep an accurate list, indication, dose, prescriber and observed effects; do not change prescribed treatment without medical advice.

7.2 Preparing for healthcare visits

- ☐ Ask whether a quieter waiting area, first/last appointment, dimmer room or reduced waiting time is possible.
- ☐ Send communication and sensory information in advance when appropriate.
- ☐ Bring a short list of symptoms, timing, what changed, medication and relevant records.
- ☐ Use visual preparation, photos, social narratives or practice with equipment if helpful.
- ☐ Ask clinicians to explain before touching or examining and to seek consent/assent as appropriate.
- ☐ Plan a preferred recovery activity after demanding appointments.



7.3 Sleep

Sleep problems are common among autistic children and can affect the whole family. Start by tracking bedtime, sleep onset, waking, naps, screens, exercise, medication, pain and the sleep environment. Discuss persistent or severe sleep problems with a qualified clinician, especially if there is snoring, breathing difficulty, suspected seizures, significant daytime sleepiness or major functional change. AAP guidance highlights sleep among common co-occurring issues that should be addressed. [7]

7.4 Feeding and nutrition

Food selectivity may involve sensory preferences, routine, oral-motor skills, gastrointestinal symptoms, anxiety or other factors. Families should avoid turning every meal into a confrontation. Seek clinical or dietetic advice when there is weight loss, poor growth, dehydration, choking, nutritional deficiency concern, very restricted intake, severe constipation or a sudden change. NICE advises against exclusion diets such as gluten- or casein-free diets for managing the core features of autism in children and young people. [4]

MEDICATION AND AUTISM

Medication may be used for specific co-occurring conditions or symptoms when clinically indicated, but medicines are not a universal treatment for the core features of autism. Decisions should be individualized, monitored and reviewed with qualified prescribers.



SECTION 8

Distress, Behaviour and Emotional Regulation

Move from “How do we stop this?” to “What is driving this, what does the person need, and what can we change?”

- Look for health, communication, sensory, demand and environmental contributors.
- Identify early signs before the person reaches crisis.
- Use post-incident learning rather than punishment or shame.

GARC PRACTICE PRINCIPLE

Distress support works best when families reduce preventable triggers, teach reliable communication, and build a recovery plan before the next difficult moment.

8.1 The GARC CALM cycle

Step	Family action
C - Check	Check immediate safety, pain/illness, communication breakdown and obvious environmental triggers.
A - Adjust	Reduce demands, language, sensory load, audience and unnecessary movement.
L - Listen	Use the person's communication; allow refusal, break requests, silence or alternative communication where safe.
M - Make a plan	After recovery, record what happened, what helped and one prevention change for next time.

8.2 Early signs are more useful than crisis signs

Early / rising stress	High distress / crisis
More scripting, pacing, repetitive questioning, withdrawal, reduced speech, covering ears, leaving tasks, faster movements, irritability	Bolting, intense crying/shouting, shutdown, aggression, self-injury, inability to process language, collapse or complete withdrawal

8.3 During high distress

- ☐ Prioritize immediate safety and reduce the number of people talking.
- ☐ Use short, familiar phrases only when needed.
- ☐ Reduce demands that can wait.
- ☐ Offer the agreed safe space or exit route.
- ☐ Avoid arguing about logic, consequences or apologies in the middle of crisis.



- ☐ Use physical intervention only where lawful, necessary, proportionate and by appropriately trained people; immediate safety takes priority.
- ☐ Seek urgent medical help if you suspect injury, medical illness, seizure, poisoning or serious risk of harm.

8.4 After the event

Recovery time matters. Some people need hours rather than minutes. Do not require immediate debriefing. When the person is ready, reconstruct the event using their preferred communication. Ask what changed in the environment, what was missed early, and what the family or team can do differently next time.

WHEN BEHAVIOUR CHANGES SUDDENLY

A marked new behaviour, loss of skills, increased self-injury, sleep disruption, withdrawal or aggression can indicate pain, illness, medication effects, mental-health difficulty or other changes. Seek appropriate clinical assessment rather than assuming the cause is autism.



SECTION 9

Safety, Safeguarding and Risk Planning

Protect the person from real risks while preserving autonomy, dignity and access to ordinary life.

- Plan for the risks that actually exist in your context.
- Teach safety skills explicitly rather than relying only on verbal warnings.
- Build backup plans for caregivers, travel, emergencies and information sharing.

GARC PRACTICE PRINCIPLE

Safety planning should reduce risk without turning family life into constant restriction. Use the least restrictive effective support and review it as skills and circumstances change.

9.1 Family risk scan

Risk domain	What to plan
Wandering / leaving supervision	Doors/exits, roads, crowds, unfamiliar places; teach identification, return and help-seeking skills.
Water	Pools, beaches, baths and open water; supervision and water-safety teaching matched to ability.
Traffic / transport	Crossing, parking lots, public transport, rideshares, cycling.
Medication / substances	Locked or controlled storage where needed; clear medication responsibility.
Fire / kitchen / tools	Visual rules, supervised practice, adapted equipment and emergency routines.
Online safety	Privacy, scams, coercion, sexual exploitation, location sharing, financial manipulation.
Abuse / exploitation	Teach body autonomy, consent, private/public distinctions, trusted people and how to report concerns.
Self-injury / suicidality	Individualized mental-health and crisis plan; urgent help for serious or immediate risk.

9.2 Emergency information card

Field	Information
Name / preferred name	
Communication	
Emergency contact 1	
Emergency contact 2	
Medical conditions / allergies	



Field	Information
Medication	
What helps in distress	
What to avoid	
Safe destination / return plan	

9.3 Safeguarding conversations should be concrete

- ☐ Teach that “no” and “stop” can be used with familiar people as well as strangers.
- ☐ Name body parts and boundaries using clear, age-appropriate language.
- ☐ Teach who may help with personal care and under what conditions.
- ☐ Create a small list of trusted people and multiple ways to report something uncomfortable.
- ☐ Do not interpret sudden fear, avoidance or behaviour change as manipulation without considering possible harm or abuse.
- ☐ Report safeguarding concerns through the appropriate local pathway.



SECTION 10

Family Wellbeing, Siblings and Caregiver Sustainability

A support plan is only durable if the family system can realistically maintain it.

- Protect caregiver health and identity, not only task performance.
- Give siblings honest, age-appropriate information and individual attention.
- Build shared responsibility and backup care before burnout or crisis.

GARC PRACTICE PRINCIPLE

Caregiver wellbeing is not separate from autism support. Sustainable routines, realistic expectations and practical support can improve life for the entire family.

10.1 Caregiver load is real

Caregivers may coordinate appointments, education, transport, sleep disruption, paperwork, behaviour support, work, finances and the needs of other family members. WHO's Caregiver Skills Training programme explicitly includes caregiver coping and, in 2026, added a dedicated caregiver-wellbeing package. [8,9] Families should treat caregiver wellbeing as an operational requirement rather than a luxury.

10.2 A caregiver sustainability check

- ☐ I have at least one person I can contact when I need practical help.
- ☐ I know who can step in if I become ill or unavailable.
- ☐ Important information is written down so support does not depend on my memory.
- ☐ I have some protected time that is not used for caregiving administration.
- ☐ I can identify early signs that I am overloaded.
- ☐ I know where I would seek professional mental-health support for myself if needed.
- ☐ Responsibilities are shared as fairly as our circumstances allow.

10.3 Siblings

Sibling need	Helpful family response
Information	Explain autism in age-appropriate language without making the sibling responsible for understanding everything.
Fairness	Explain that fair does not always mean identical, while still protecting the sibling's own needs and boundaries.
Individual attention	Schedule predictable one-to-one time and protect the sibling's activities where possible.
Emotional permission	Make it safe to feel love, frustration, embarrassment, pride, anger or worry without guilt.
Boundaries	Do not automatically assign the sibling a lifelong caregiving role; future roles should be discussed, chosen and planned.



10.4 Respite and practical help

Respite can mean formal short breaks, a trained sitter, extended family, a community programme, shared transport, meal support or simply someone taking over paperwork for an hour. NICE recommends offering families and carers information and assessment of their own support needs, including practical support and short breaks, within the UK system; equivalent services vary internationally. [4]



SECTION 11

Puberty, Relationships, Sexuality and Consent

Prepare early and teach explicitly what other young people may learn indirectly.

- Use clear language about bodies, privacy, hygiene, relationships and consent.
- Respect sexuality and identity without assuming interest or disinterest.
- Include online relationships and exploitation prevention in safety education.

GARC PRACTICE PRINCIPLE

Autistic people have the same right to accurate, age-appropriate information, privacy, safety and respectful relationships as anyone else. Teaching should be concrete, repeated and individualized.

11.1 Start before puberty changes arrive

- ☐ Name expected body changes and when they may happen.
- ☐ Create visual or written hygiene routines where useful.
- ☐ Prepare for menstruation, shaving, deodorant, body odour, erections, ejaculation or other relevant changes without shame.
- ☐ Teach private versus public actions and places using specific examples.
- ☐ Plan for sensory needs related to hygiene products, clothing and body changes.

11.2 Consent must be teachable and usable

Concept	Concrete teaching point
My body	I can say no to touch except in limited safety/health situations that should still be explained.
Other people's bodies	I need permission before touching, hugging, kissing or sexual contact.
Changing your mind	A yes can become a no. Silence, freezing or lack of resistance is not a clear yes.
Power and pressure	Someone who uses threats, money, secrets, status or repeated pressure is not respecting consent.
Digital consent	Do not share intimate images or private information without explicit permission; get help if someone pressures or threatens you.

11.3 Relationships and social learning

Avoid teaching only rigid rules such as “always hug relatives” or “never talk to strangers.” Real life requires context. Teach categories of relationships, degrees of trust, reciprocity, boundaries, rejection, repair and how to get help. For adults, NICE advises sensitivity to sexuality and the risk of misunderstanding or exploitation. [6]



SECTION 12

Adolescence, Adulthood and Future Planning

Shift gradually from parent-managed support to adult life built around the person's goals, rights and required supports.

- Start transition planning early enough to practise real skills.
- Plan across education, health, employment, relationships, money, living and decision-making.
- Do not equate adulthood with withdrawal of needed support.

GARC PRACTICE PRINCIPLE

The destination is not “independence at all costs.” It is an adult life with maximum self-determination, meaningful participation and the right supports.

12.1 Transition domains

Domain	Questions to plan
Education / training	What learning pathway fits strengths, interests, accommodations and long-term goals?
Employment	What tasks, environments, schedules and supports fit? Is supported employment useful?
Health	Who will coordinate adult healthcare? Can the person describe health needs and consent preferences?
Daily living	Which skills are independent, shared or supported? What technology or routines help?
Housing	What living arrangements are preferred and feasible? What support is needed day and night?
Money	What budgeting, benefits, banking or financial safeguards are needed?
Relationships	How will the person build friendships, community roles and intimate relationships if desired?
Decision-making	What decisions can the person make independently, with support, or through legally recognized arrangements? Local law varies.
Safety	What changes when the person travels alone, works, dates, lives away from family or uses money independently?

12.2 Employment and meaningful activity

NICE recommends considering individualized supported employment for autistic adults who need help obtaining or maintaining work, including job matching, role preparation, employer support and ongoing assistance. [6] Families can begin earlier by identifying interests, tolerable environments, stamina, communication needs, transport options and the difference between a hobby, a volunteer role and paid work.



12.3 Decision-making and legal planning

Decision-making laws differ by country. Families should avoid assuming that an autism diagnosis automatically removes decision-making rights. Where support is needed, explore the least restrictive lawful approach and seek qualified local legal advice about powers of attorney, supported decision-making, guardianship or equivalent arrangements. GARC does not provide jurisdiction-specific legal advice through this toolkit.

12.4 Build the “what if I am not available?” file

- ☐ Daily routine and communication profile
- ☐ Health and medication summary
- ☐ Financial and benefits information where appropriate
- ☐ Education/employment contacts
- ☐ Important relationships
- ☐ Sensory and distress support
- ☐ Safety risks and emergency plan
- ☐ Preferred activities, interests and routines
- ☐ Legal/decision-making documents if applicable
- ☐ Names of people willing and able to take defined roles



SECTION 13

Choosing Services, Therapies and Interventions Wisely

Use evidence, fit, burden, safety and measurable outcomes - not marketing pressure - to decide what deserves time and money.

- Define the specific problem or goal before choosing a service.
- Ask what evidence supports the intervention for that goal and population.
- Measure benefit and burden, and stop or change plans that are not helping.

GARC PRACTICE PRINCIPLE

“Autism treatment” is too broad a category. Choose interventions for a defined need: communication, anxiety, sleep, daily living, learning, safety, pain, mental health or another concrete goal.

13.1 The GARC 9-question provider test

1. What specific outcome is this service trying to improve?
2. How will we measure whether it is helping?
3. What evidence supports it for people with similar needs and age?
4. What training, qualifications and supervision does the provider have?
5. What are the known risks, side effects, costs and opportunity costs?
6. How will the autistic person's assent, preferences and distress signals be respected?
7. How much time will this take from school, sleep, family life, play, work or community participation?
8. What is the review date and what would make us stop, change or continue?
9. Can the provider coordinate with the rest of the person's team rather than operating in isolation?

13.2 Marketing red flags

- ☐ Guaranteed outcomes or claims to “cure” autism
- ☐ Pressure to buy quickly or pay large sums before assessment
- ☐ A provider who discourages questions or independent medical advice
- ☐ Secret methods, proprietary tests or explanations that cannot be evaluated
- ☐ Claims that one intervention works for every autistic person
- ☐ Requiring painful, humiliating or coercive practices for ordinary harmless autistic behaviour
- ☐ Telling families to stop prescribed treatment without the prescriber
- ☐ Using testimonials as the main evidence while avoiding discussion of risks or limitations

13.3 Evidence does not remove individual choice

A well-supported intervention can still be a poor fit for a particular person because of goals, sensory needs, time burden, values, access or side effects. Conversely, families may use low-risk supportive strategies that are not “treatments” at all, such as visual schedules, communication supports, environmental adjustments or



structured routines. Shared decision-making should combine evidence, professional expertise and the autistic person's and family's priorities.

13.4 Interventions specifically discouraged by major guidance

Families should be especially cautious about biomedical or dietary approaches promoted as treatments for the core features of autism. NICE guidance advises against exclusion diets for the core features of autism in children and adults, and against chelation, hyperbaric oxygen and several other biomedical approaches for autistic adults. [4,6] Do not start restrictive diets, high-dose supplements or medical procedures without qualified clinical oversight.



SECTION 14

Working With Professionals and Coordinating Care

Turn multiple appointments and providers into one coherent support plan.

- Assign clear roles and keep a single current summary of goals, health and supports.
- Ask providers to explain recommendations in plain language and link them to measurable outcomes.
- Prevent families from becoming the only information system connecting services.

GARC PRACTICE PRINCIPLE

Coordination is a clinical and practical intervention in its own right. When everyone works from a shared profile and priorities, families spend less energy repeating the same story.

14.1 Build your team map

Role / service	What they contribute	Main contact / next review
Primary care / paediatrics		
Autism / developmental service		
Speech and language / communication		
Occupational therapy		
Mental health		
Education / SEN / disability support		
Social care / community support		
Employment / vocational		
Other specialist		

14.2 Prepare for appointments

- ☐ Write the top three questions before the appointment.
- ☐ Bring a short timeline rather than every document you own.
- ☐ List current medication, supplements and allergies accurately.
- ☐ Describe change using examples: when, how often, how long, what happened before and after.
- ☐ Ask: "What are the options?" "What are the risks?" "What should we expect?" "When should we review?"
- ☐ Request accessible written instructions when needed.
- ☐ Confirm who is responsible for each follow-up action before leaving.



14.3 Ask for a shared problem definition

EXAMPLE

Instead of “We need to fix aggression,” define: “During unexpected evening transitions, he sometimes hits his head and pushes others. We need to rule out pain, reduce transition uncertainty, create a reliable break request, and make the environment safe while we track frequency and recovery.”

14.4 When professional opinions conflict

Ask each professional to state the goal, evidence, assumptions, risks and what outcome would change their recommendation. Seek a second opinion when the stakes are high, the diagnosis remains uncertain, or recommendations conflict materially. For children and young people, NICE explicitly allows for second opinion in circumstances such as continued diagnostic uncertainty or disagreement. [5]



SECTION 15

GARC Family Tools, Templates and Checklists

Reusable pages for appointments, home routines, education meetings, safety planning and long-term coordination.

- Complete only the tools that solve a real problem.
- Keep documents short enough that other people will actually read them.
- Review dated information rather than letting old assumptions become permanent.

GARC PRACTICE PRINCIPLE

A good family document is current, specific and useful at the moment it is needed. Keep a master copy and update it after meaningful changes.

15.1 My Autism Support Profile

Field	Information
Name / preferred name	
Age / date of birth	
Preferred language / communication	
Important strengths / interests	
How I show “yes”	
How I show “no / stop”	
How I ask for help / break	
Sensory preferences / triggers	
Early signs of stress	
What helps me regulate	
Health conditions / allergies	
Medication	
Important routines	
Safety considerations	
Please do not assume...	
The best way to support me is...	



15.2 Communication Passport

Situation	What helps
When giving me instructions	
When I need more processing time	
When I cannot use speech reliably	
When I am in pain	
When I am anxious or overwhelmed	
When I disagree	
When I need privacy	
When meeting a new professional	

Key words / symbols / messages to keep available

Message	How I express it
Yes	
No	
Stop	
Help	
Break	
Pain	
Toilet	
Hungry / thirsty	
Finished	
I do not understand	



15.3 Sensory and Regulation Profile

Area	Usually okay	Can be difficult	What helps
Sound			
Light / visual			
Touch / clothing			
Smell			
Taste / food texture			
Movement / balance			
Crowds / proximity			
Temperature			
Pain / internal body signals			

My early stress signs

- ☐ _____
- ☐ _____
- ☐ _____

My recovery options

- ☐ _____
- ☐ _____
- ☐ _____



15.4 Healthcare Visit Preparation Sheet

Before the visit	Notes
Reason for appointment	
Main symptoms / change	
When it started	
What makes it better / worse	
Current medication / supplements	
Allergies	
Communication needs	
Sensory adjustments requested	
Questions to answer today	1. 2. 3.
Follow-up / tests / referrals	

After the visit

- ☐ I understand what the clinician thinks may be happening.
- ☐ I understand what to do next.
- ☐ I know what side effects or warning signs to watch for.
- ☐ I know when and how follow-up will happen.
- ☐ I have written instructions in a format we can use.



15.5 Medication and Symptom Log

Date	Medication / dose / time	Target symptom	Observed benefit	Possible side effect / concern

SAFETY NOTE

Do not start, stop or change prescribed medication based only on this log. Use it to provide accurate information to the prescriber.



15.6 Distress and Crisis Prevention Plan

Stage	What it looks like for me	What supporters should do
Baseline / regulated		
Early stress		
Rising distress		
High distress / crisis		
Recovery		

Things that increase risk

- ☐ _____
- ☐ _____

Emergency threshold

Use local urgent medical, crisis or emergency services when:



15.7 Home Routine Builder

Routine	Step	Prompt / support	Can support be faded?
Morning	1.		
	2.		
	3.		
Evening	1.		
	2.		
	3.		

Transition support

- ☐ Advance warning: _____
- ☐ Visual cue: _____
- ☐ Completion ritual: _____
- ☐ Preferred next-step support: _____



15.8 Family-School / Service Communication Page

Date	What changed?	What worked?	What did not help?	Action / owner

KEEP IT USEFUL

Use this for meaningful patterns and decisions, not constant surveillance. The autistic person's privacy and dignity still matter.



15.9 Provider / Intervention Decision Checklist

Question	Yes / No / Notes
The target outcome is specific and important to the autistic person/family.	
The provider explained evidence and limitations.	
Qualifications and supervision are clear.	
Risks and side effects were discussed.	
Cost and time burden are acceptable.	
The plan respects communication, assent and dignity.	
Progress will be measured.	
There is a review date.	
There are clear criteria to stop or change the plan.	
The service will coordinate with relevant professionals.	



15.10 Transition to Adulthood Checklist

- ☐ Autistic person's own goals have been discussed in an accessible way.
- ☐ Adult healthcare pathway identified.
- ☐ Communication and accommodation needs documented.
- ☐ Education/training/employment options explored.
- ☐ Travel and community access practised where relevant.
- ☐ Daily living skills mapped: independent / supported / not yet taught.
- ☐ Money and financial safeguards planned.
- ☐ Housing preferences and support needs discussed.
- ☐ Relationship, sexuality and online-safety education included.
- ☐ Legal decision-making options reviewed with qualified local advice where needed.
- ☐ Emergency and backup caregiver plan updated.
- ☐ Important records organized and accessible to authorized people.



15.11 Family Review: Every 90 Days

Review question	Notes
What improved in the last 90 days?	
What became harder?	
What does the autistic person say matters now?	
Any new health or medication issues?	
Any new safety risk?	
Which support should we keep?	
Which support should we change or stop?	
What can be simplified?	
What is the family's top priority for the next 90 days?	
Who owns the next actions?	



Appendix A - Role-Specific Quick Guides

Parents / primary caregivers

- ☐ Keep a current one-page profile rather than relying on verbal explanations.
- ☐ Protect ordinary family life: sleep, meals, play, relationships and rest are outcomes too.
- ☐ Choose a few priorities and review them; more services are not automatically better.
- ☐ Track new health or behaviour changes and escalate concerns appropriately.
- ☐ Create backup care before a crisis.

Grandparents and extended family

- ☐ Follow the communication and sensory strategies the person already uses.
- ☐ Do not interpret reduced eye contact, delayed replies or need for routine as rudeness.
- ☐ Ask before hugging or touching.
- ☐ Support parents without turning every interaction into advice.
- ☐ Learn emergency and safety information if you provide care.

Siblings

- ☐ You are allowed to have your own needs, plans and feelings.
- ☐ You are not responsible for being a therapist or replacement parent.
- ☐ Ask adults for clear explanations when something is confusing.
- ☐ Protect your own privacy and boundaries.
- ☐ Future caregiving roles should be choices discussed openly, not assumptions.

Babysitters / respite / support workers

- ☐ Read the one-page profile before being left in charge.
- ☐ Know communication, allergies, medication responsibilities, safety risks and emergency contacts.
- ☐ Follow established routines unless there is a good reason to change them.
- ☐ Avoid unnecessary demands during stress.
- ☐ Document significant incidents accurately and factually.



Appendix B - Choosing Reliable Information

Autism information is abundant, but quality varies. Prefer sources that are transparent about evidence, authorship, conflicts of interest, dates, limitations and the difference between research findings and personal experience.

Stronger information signal	Caution signal
National or international health guidance with methods and references	Anonymous website with no source trail
Peer-reviewed research or systematic reviews interpreted cautiously	One dramatic study presented as final proof
Clear distinction between association and causation	Claims that one factor “causes” all autism
Specific population, outcomes and limitations	Universal claims applying to every autistic person
Balanced discussion of benefit, harm and uncertainty	Testimonials, urgency and fear used to sell a product
Date and update history	Old content presented as current without review

EVIDENCE HIERARCHY IS NOT THE WHOLE DECISION

Strong evidence can still require individual adaptation. Lived experience can reveal important problems and preferences but does not by itself establish that a treatment is effective. Use both appropriately.



Appendix C - Glossary

Term	Plain-language meaning
AAC	Augmentative and alternative communication; methods that supplement or replace speech, including symbols, boards, devices, sign and text.
Accommodation / adjustment	A change to an environment, process or expectation that improves access or participation.
Autistic burnout	A term used by some autistic people to describe profound exhaustion and reduced capacity associated with sustained demands and inadequate recovery; it is not a formal diagnostic category.
Co-occurring condition	A health, mental-health or neurodevelopmental condition that exists alongside autism.
Executive functioning	Mental processes involved in planning, starting, stopping, switching, organizing, working memory and self-monitoring.
Interoception	Perception of internal body signals such as hunger, thirst, pain, temperature, heart rate or needing the toilet.
Meltdown	A non-clinical term often used for an intense loss of regulation under overwhelming conditions; it should not automatically be interpreted as intentional misconduct.
Neurodiversity	The idea that human brains and nervous systems vary; in practice, the term is often used to support respect for neurological differences alongside recognition of disability and support needs.
Shutdown	A non-clinical term often used for a marked reduction in speech, movement or interaction during overload or exhaustion.
Stimming	Repetitive movement, sound or other sensory behaviour that may support regulation, expression or enjoyment.
Supported decision-making	Approaches that help a person understand, consider and communicate decisions while preserving their decision-making role where legally applicable.



Appendix D - Selected Authoritative Resources

Source	Useful for	Website
World Health Organization (WHO)	Autism fact sheet; Caregiver Skills Training for families of children with developmental delays or disabilities.	who.int
U.S. Centers for Disease Control and Prevention (CDC)	Autism signs, screening, diagnosis and accessing services.	cdc.gov/autism
National Institute of Mental Health (NIMH)	Autism overview and mental-health information.	nimh.nih.gov
National Institute for Health and Care Excellence (NICE)	Guidelines for autism recognition, support and management in children, young people and adults.	nice.org.uk
American Academy of Pediatrics (AAP)	Clinical report on identification, evaluation and management of children with autism spectrum disorder.	publications.aap.org

LOCAL SERVICES

Eligibility, education rights, safeguarding duties, benefits, respite, guardianship and emergency pathways vary by country and sometimes by region. Use this toolkit with verified local information.



References and Evidence Notes

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<https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>
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<https://www.cdc.gov/autism/diagnosis/index.html>
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4. **National Institute for Health and Care Excellence.** Autism spectrum disorder in under 19s: support and management (CG170). Published 2013; last updated 14 June 2021. <https://www.nice.org.uk/guidance/cg170>
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7. **Hyman SL, Levy SE, Myers SM, et al.** Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. *Pediatrics*. 2020;145(1):e20193447. Clinical report reaffirmed October 2025.
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10. **Centers for Disease Control and Prevention.** Accessing Services for Autism Spectrum Disorder. Updated 15 April 2025.
<https://www.cdc.gov/autism/treatment/accessing-services.html>

EVIDENCE NOTE

This toolkit prioritizes practical translation of authoritative guidance and does not attempt to reproduce every recommendation from the source documents. Readers should consult the original source for full methods, scope and recommendation wording.



GARC Family Action Summary

Use this final page as the handoff sheet between family members and professionals. Keep it short.

Current top priority	Action	Owner	Review date

The person’s voice

What matters to me now:

What I want people to understand about me:

Keep / Change / Stop

KEEP because it helps	CHANGE because...	STOP because...

GARC CLOSING PRINCIPLE

Support should help an autistic person live a safer, healthier, more connected and more self-directed life - not simply look more typical to other people.