



# HEALTHCARE PROFESSIONAL AUTISM TOOLKIT

A Practical Evidence-Informed Guide for Accessible Communication, Clinical Encounters,  
Sensory Support, Safety and Continuity of Care

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# Publication Information

## Purpose and audience

This toolkit supports physicians, nurses, allied health professionals, emergency teams, dentists, pharmacists, mental health professionals, administrators, reception staff, diagnostic services and other healthcare workers who want to make care safer, more accessible and more responsive for autistic children, adolescents and adults.

## Scope

The toolkit focuses on access to healthcare, communication, sensory environments, preparation for examinations and procedures, symptom recognition, pain and distress, preventive care, urgent and inpatient care, medication conversations, family and supporter involvement, transitions, safeguarding, privacy, discharge and quality improvement. It is not a disease-specific treatment manual.

## Clinical and legal notice

This publication is an educational and institutional practice resource. It does not replace clinical judgment, local law, professional standards, emergency protocols, safeguarding duties, prescribing guidance, consent and capacity law, or individualized medical advice. New or acute symptoms should be assessed on their clinical merits; autism should not be used as an explanation that delays investigation of physical or mental illness.

## Language, dignity and agency

The toolkit generally uses identity-first language ("autistic person") while recognizing that individuals may prefer different terminology. Healthcare teams should ask and respect communication preferences, decision-making preferences, privacy, cultural context and the person's right to participate in decisions about their care.

## Evidence approach

The guidance is informed by international rights frameworks, WHO information on autism and health, NICE autism guidance, accessible-healthcare resources developed with autistic people, and principles of person-centred, trauma-informed and equitable care. Local clinical pathways should always be checked before implementation.

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## Foreword

Healthcare is often designed around speed, spoken communication, unfamiliar environments, waiting, rapid transitions and assumptions about how pain, distress and cooperation should look. These conditions can create avoidable barriers for autistic people even when the underlying clinical care is technically excellent.

The practical challenge is not to make every encounter identical. It is to preserve clinical standards while adapting the route by which a person can understand, communicate, tolerate, consent to and recover from care. Small changes - clearer information, fewer surprises, sensory adjustments, direct language, extra processing time and better handover - can materially change safety and experience.

Autistic people are diverse. Some communicate primarily through speech; others use AAC, writing, gestures, a supporter, or a combination of methods. Some have intellectual disability, epilepsy or complex health needs; others do not. Some need extensive adjustments; others need only a few predictable changes. The correct starting point is the individual, not a stereotype.

This toolkit is designed to help healthcare organizations move from goodwill to repeatable practice. It combines a 10-point framework with clinical encounter guidance and practical tools that can be embedded into outpatient, inpatient, emergency, diagnostic, dental, pharmacy and community services.

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## Quick navigation

Clinical teams can use individual sections independently, but organizations should implement the 10-point framework and the tools together so that adjustments survive staff changes and care transitions.

# How to Use This Toolkit

Use this toolkit at three levels:

| Level        | Primary users                                             | Use                                                                                                       |
|--------------|-----------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|
| Encounter    | Clinicians, nurses, allied health, reception              | Prepare the person, reduce barriers, communicate clearly and record what works.                           |
| Service      | Clinic leads, ward managers, quality teams                | Standardize accessible processes, waiting options, flags, handovers and staff capability.                 |
| Organization | Executives, governance, patient experience, digital teams | Measure access, embed policy, improve estates and digital systems, and include autistic people in design. |

## Core principle

Do not ask, “How do we make the autistic person fit the service?” Ask, “What barriers in the service are preventing safe and effective care, and what clinically appropriate adjustments remove them?”

## Use alongside local protocols

The toolkit should sit beside local protocols for emergency medicine, medicines management, infection prevention, safeguarding, consent and capacity, restraint, mental health crisis, perioperative care, complaints, incident reporting, data protection and disability access.

## SECTION 01

# Understanding Autism in Healthcare

*A clinical-access foundation for every member of the healthcare team.*

- Autism is a diverse neurodevelopmental condition; healthcare access needs vary substantially between people and across situations.
- Communication differences, sensory processing, uncertainty, executive demands and previous healthcare experiences can alter how a person presents.
- Apparent cooperation, eye contact or fluent speech do not reliably indicate comprehension, consent, pain level or internal distress.

## Autism is not a single clinical presentation

Autistic people differ in language, cognition, sensory processing, movement, self-regulation, interoception, adaptive functioning and support needs. A person may have strong verbal ability yet struggle to answer open-ended questions under stress. Another person may communicate reliably through AAC, writing, pictures, gestures or a familiar supporter.

## Healthcare barriers can change presentation

- Bright lighting, alarms, crowded waiting rooms, touch, smells and unpredictable noise may increase sensory load.
- Rapid questioning, figurative language and multiple speakers can make communication harder.
- Long waits and uncertain sequences can increase distress or shutdown.
- Masking may conceal difficulty until the person becomes exhausted or overwhelmed.
- Past coercive or painful healthcare experiences can increase fear and avoidance.

## Co-occurring health needs

Autistic people may have the same acute, chronic, preventive, reproductive, dental and mental health needs as anyone else, and some may also have co-occurring epilepsy, gastrointestinal problems, sleep difficulties, anxiety, ADHD, intellectual disability or other conditions. Do not attribute new symptoms automatically to autism.

### Diagnostic overshadowing risk

When behavior or distress changes, consider pain, illness, injury, medication effects, sleep, constipation, infection, mental health and other medical causes before assuming the change is “because of autism.”

## SECTION 02

# GARC 10-Point Autism-Inclusive Healthcare Framework

*A shared operating model for accessible, safe and person-centred care.*

- Use the framework across outpatient, inpatient, emergency, primary, dental, diagnostic and community care.
- Combine universal accessibility with individualized adjustments.
- Measure whether people can obtain, understand, tolerate, complete and continue care - not merely whether a policy exists.

| #  | Domain                          | Practice standard                                                                             |
|----|---------------------------------|-----------------------------------------------------------------------------------------------|
| 1  | Prepare                         | Offer clear pre-visit information and a route to request adjustments.                         |
| 2  | Communicate                     | Use direct, concrete communication and the person's preferred method.                         |
| 3  | Reduce sensory load             | Adjust lighting, noise, waiting, touch and environmental demands when possible.               |
| 4  | Make time visible               | Explain sequence, duration, delays and what happens next.                                     |
| 5  | Support autonomy                | Seek consent, offer choices and use supported decision-making appropriately.                  |
| 6  | Recognize atypical presentation | Use baseline knowledge and avoid relying on facial expression or typical pain behavior alone. |
| 7  | Coordinate                      | Share relevant access information across services with appropriate consent and privacy.       |
| 8  | Plan transitions                | Prepare transfers, admissions, discharge and changes in clinician or setting.                 |
| 9  | Escalate safely                 | Have clear plans for distress, crisis, safeguarding and urgent deterioration.                 |
| 10 | Improve with data               | Include autistic people in design, review incidents and measure access outcomes.              |

## Minimum Organizational Standard

Use this page as a governance-level minimum for a clinic, department or hospital service.

- ☐ A documented process for recording reasonable or equivalent access adjustments.
- ☐ A visible pathway for communication preferences and supporter involvement.
- ☐ A mechanism to reduce waiting or offer alternative waiting locations when clinically feasible.
- ☐ A staff guide for distress, sensory overload and least-restrictive de-escalation.
- ☐ A handover standard so access information follows the person through the episode of care.

### Governance questions

- Where is access information recorded, and can every relevant team see it?
- Who is accountable when an agreed adjustment is not delivered?
- Which incidents involving distress, restraint, delayed diagnosis or failed procedures are reviewed for accessibility factors?
- How are autistic patients and families involved in redesign and feedback?

#### Implementation test

A policy is not implemented until frontline staff can identify the adjustment, deliver it consistently, and hand it over to the next team.

## SECTION 03

# Access, Scheduling and Pre-Visit Planning

*Reduce uncertainty before the patient reaches the clinical room.*

- Accessibility begins when the appointment is booked, not when the clinician enters.
- Pre-visit information should explain where to go, what will happen, who will be present and how long the visit may take.
- Offer an easy way to request communication, sensory, timing or supporter adjustments.

## Booking and scheduling

- Offer online, written or proxy-supported booking routes in addition to telephone where feasible.
- Ask whether the person needs extra time, a quieter slot, reduced waiting, a supporter, written communication, AAC access or another adjustment.
- Avoid requiring the person to retell the same access needs at every contact.
- For complex visits, consider first/last appointments, coordinated appointments or a pre-visit call when clinically appropriate.

## Pre-visit information

| Include             | Example                                                                                      |
|---------------------|----------------------------------------------------------------------------------------------|
| Purpose             | "This appointment is to review your breathing symptoms and decide whether tests are needed." |
| Sequence            | Check-in → wait → nurse observations → clinician conversation → examination → plan.          |
| Sensory information | Possible blood-pressure cuff, bright examination light, gel, adhesive or monitor sounds.     |
| Duration            | Expected appointment time and whether waiting is likely.                                     |
| Preparation         | Fasting, medication, clothing, specimen or document requirements stated explicitly.          |
| Contact             | Named service route for adjustment questions or changes.                                     |

### Avoid surprise when avoidable

If a procedure, touch, positioning requirement or sensory exposure is reasonably foreseeable, explain it before the visit. Preparation is an access intervention, not an optional courtesy.

## SECTION 04

# Communication and Supported Decision-Making

*Make information understandable and preserve the person's agency.*

- Ask how the person communicates best when well and when stressed.
- Use plain, literal language; allow processing time and one speaker at a time.
- Support decision-making without automatically transferring decisions to family or supporters.

## Practical communication standard

- Introduce yourself and your role.
- State the purpose of the encounter before asking questions.
- Ask one clear question at a time.
- Avoid idioms, vague phrases and implied instructions.
- Allow silence for processing; do not repeatedly rephrase too quickly.
- Use written options, visual supports, body diagrams or rating scales when helpful.
- Check understanding by asking the person to explain the plan in their own preferred way, rather than simply asking "Do you understand?"

## AAC and alternative communication

Do not remove or separate a person from their communication device unless there is an immediate safety reason. Ensure charging, positioning, access method and communication partner support are considered during examination, imaging, procedures and inpatient care.

## Consent and capacity

Follow applicable law and professional standards. Autism alone does not establish incapacity. Provide accessible information, reduce environmental barriers, offer time and appropriate support, and assess the specific decision rather than making global assumptions about competence.

### Supporter role

A supporter can clarify history, baseline behavior and communication, but the clinician should address the autistic person directly whenever possible and confirm what information may be shared.

## SECTION 05

# Sensory Environment, Waiting and Flow

*Design care pathways that reduce preventable overload.*

- Noise, light, crowding, smell, touch and movement can directly affect a person's ability to communicate and tolerate care.
- Waiting is often a clinical-access issue because uncertainty and sensory exposure compound over time.
- Adjust the environment where possible; when not possible, make the exposure predictable and time-limited.

## High-impact adjustments

| Barrier              | Possible adjustment                                                                               |
|----------------------|---------------------------------------------------------------------------------------------------|
| Crowded waiting area | Alternative waiting location, text alert, wait outside or in vehicle where safe.                  |
| Lighting             | Dim lights, use natural light or allow sunglasses/cap if clinically compatible.                   |
| Noise                | Quiet room, reduce unnecessary alarms, allow headphones or ear defenders.                         |
| Touch                | Explain before contact, ask permission, use firm rather than unexpected light touch if preferred. |
| Smell                | Avoid unnecessary fragranced products; prepare the person for strong antiseptic or dental odors.  |
| Uncertain delay      | Give updated time estimates and explain what is causing the delay.                                |

## Flow matters

A short, well-prepared encounter may be safer than a long visit that exhausts the person. Where clinically appropriate, coordinate tasks, minimize repeated room changes, complete the most important elements first and consider staged visits for non-urgent care.

## SECTION 06

# Clinical History, Examination and Procedures

*Preserve diagnostic quality while making the encounter tolerable.*

- Build the history using multiple sources when appropriate: patient report, written information, supporter input, records and objective measures.
- Explain examination steps before touching or moving equipment.
- Break procedures into predictable stages and distinguish essential from optional elements.

## History taking

- Ask about the person's usual baseline before interpreting a change.
- Use concrete time anchors: today, yesterday, last week, before/after a known event.
- Offer body diagrams or symptom lists when open-ended questions are difficult.
- Ask about sleep, appetite, bowel/bladder changes, mobility, medication changes and recent stressors when relevant.
- Document reliable signs of pain, illness or overload for future visits.

## Examination

1. Tell the person what you need to examine and why.
2. Describe what they may feel, hear or see.
3. Ask permission before touch whenever possible.
4. Offer a stop signal or pause method.
5. Proceed from least invasive to more demanding steps when clinically safe.
6. Record which approaches worked or failed.

## Procedures and investigations

For blood tests, imaging, dental procedures, ECGs, dressings or other procedures, consider rehearsal, photos, social or visual sequences, topical or procedural comfort measures according to local protocols, preferred positioning, familiar supporters, sensory modifications and scheduling that minimizes waiting. Sedation decisions require formal clinical assessment and should never be treated as the default response to autism.

## SECTION 07

# Pain, Interoception and Symptom Recognition

*Do not rely on typical pain behavior alone.*

- Pain expression can be atypical, delayed, minimized, exaggerated or expressed through changes in behavior or function.
- Interoceptive differences may affect recognition or description of internal sensations.
- Use the person's baseline, objective assessment and collateral information when appropriate.

## Possible indicators of pain or illness

- Sudden withdrawal or reduced communication.
- Increase in repetitive movement, agitation or self-injury.
- Change in sleep, appetite, toileting or mobility.
- New avoidance of touch, food, movement or a particular body position.
- Loss of previously stable skills or routines.
- Unexplained fatigue, shutdown or distress.

### Clinical safety

Behavior change is information, not a diagnosis. Evaluate plausible medical causes and do not withhold investigation solely because a person cannot describe symptoms conventionally.

## Pain assessment

Use the most appropriate validated pain assessment approach available for the person's age, communication and cognitive profile, together with individualized baseline information. Ask what pain looks like for this person and what communication method is most reliable when they are unwell.

## SECTION 08

# Primary, Preventive and Long-Term Care

*Make routine healthcare as accessible as acute care.*

- Preventive care reduces avoidable illness but can be lost when services are difficult to access or tolerate.
- Long-term condition management should not assume that complex self-management instructions are automatically accessible.
- Care plans should identify how information, monitoring and follow-up will actually work for the individual.

## Preventive care checklist

- ☐ Use ordinary age- and risk-appropriate preventive care and screening unless a clinical reason indicates otherwise.
- ☐ Explain screening procedures and preparation in accessible formats.
- ☐ Plan vaccinations, dental care, blood monitoring and other recurring procedures around known sensory or communication needs.
- ☐ Check whether letters, portal messages and medication instructions are understandable.
- ☐ Offer structured follow-up rather than relying only on the person to initiate contact after deterioration.

## Long-term conditions

For diabetes, asthma, epilepsy, gastrointestinal disease, cardiovascular risk, chronic pain or other long-term conditions, simplify monitoring routines, make thresholds explicit, document escalation instructions and involve the person in choosing sustainable methods. Avoid creating plans that are theoretically correct but impossible to follow because of executive, sensory or communication barriers.

## SECTION 09

# Emergency, Urgent and Acute Care

*Act quickly without losing accessibility and diagnostic discipline.*

- Emergency environments are inherently sensory-intense and unpredictable; accessibility must be rapid and pragmatic.
- Distress can reflect pain, fear, sensory overload, communication breakdown or medical deterioration.
- Clinical urgency takes priority, but unnecessary coercion, repeated questioning and avoidable sensory load should be minimized.

## First 5 minutes

1. Identify immediate clinical risk and time-critical treatment needs.
2. Ask the person or supporter for the fastest communication method and critical access information.
3. Reduce nonessential people, noise and repeated questioning where possible.
4. Find out what “usual” behavior, movement, speech and responsiveness look like for this person.
5. Explain each urgent action in the shortest clear language possible.

## Handover

Include access needs in clinical handover: communication method, effective calming strategies, sensory triggers, supporter role, pain indicators, essential routines, known risks and what has already been explained. This information should complement - not replace - the medical handover.

### Do not miss deterioration

A change in behavior or communication may be an early sign of pain, infection, hypoxia, medication effect, neurological change or another acute problem. Reassess clinically when the presentation changes.

## SECTION 10

# Mental Health, Distress and Crisis

*Differentiate distress from danger and respond with the least restrictive safe approach.*

- Anxiety, depression and other mental health conditions can co-occur with autism and may present differently.
- Overload, shutdown and meltdown are not diagnoses; they are states that require understanding of triggers, safety and recovery needs.
- Use local crisis, suicide-risk, safeguarding and emergency protocols whenever indicated.

## When distress escalates

- Reduce language and the number of people speaking.
- Lower sensory demands where safe.
- Give physical space and time to process.
- Avoid forcing eye contact.
- Use familiar communication and agreed coping strategies.
- Clarify whether the person wants a supporter present.
- Escalate to clinical mental health assessment when there are concerns about suicidality, psychosis, severe depression, acute risk or other psychiatric emergencies.

## After the event

When the person is regulated, review what happened: antecedents, communication breakdowns, environmental factors, pain or illness, staff actions that helped or worsened the situation, and what should be documented for future care. Incident review should look for system causes, not only individual behavior.

## SECTION 11

# Medication, Consent and Treatment Adherence

*Make treatment plans understandable, monitorable and realistic.*

- Medication conversations should separate indication, expected benefit, common risks, monitoring and what to do if problems occur.
- Adherence difficulties may reflect sensory, swallowing, routine, executive or communication barriers rather than refusal.
- Prescribing and administration must follow local professional standards and medicines governance.

## Accessible medication conversation

| Question to answer  | Example format                                                                      |
|---------------------|-------------------------------------------------------------------------------------|
| Why?                | What problem is this medicine intended to treat?                                    |
| How?                | Exact dose, timing, route and whether food matters - according to the prescription. |
| What to expect?     | When benefit may be noticed and which common side effects matter.                   |
| What requires help? | Clear red flags and contact route using local clinical guidance.                    |
| How will we review? | Date, monitoring tests, outcome measures and who is responsible.                    |

## Barriers to adherence

- Taste, texture, smell or swallowing difficulty.
- Complex schedules or changing routines.
- Difficulty noticing or describing side effects.
- Unclear purpose or fear based on past experience.
- Packaging, dexterity or literacy barriers.
- Multiple prescribers or inconsistent instructions.

### Safety boundary

Do not alter formulation, crush tablets, split doses or change administration methods unless the relevant medicine can safely be used that way and the change is approved through appropriate clinical/pharmacy guidance.

## SECTION 12

# Children, Adolescents and Family Partnership

*Support the child's voice while using family knowledge appropriately.*

- Parents and caregivers often hold critical information about baseline health, communication, sensory needs and pain behavior.
- Children and adolescents should still be addressed directly and included in decisions in developmentally appropriate ways.
- Prepare for increasing autonomy, privacy and transition to adult services before the handover point.

## Family as partner, not substitute

Families may know how a child communicates illness, tolerates examination and recovers from distress. Use that knowledge while preserving the child's dignity, privacy and opportunities for choice. Ask what information the young person wants shared as they mature and follow local consent/confidentiality requirements.

## Procedure preparation for children

- Use pictures or short step-by-step explanations.
- Allow practice with non-clinical equipment when appropriate.
- Offer predictable choices such as which arm, position or sequence when clinically safe.
- Use the child's preferred comfort object, activity or communication support.
- Plan recovery time after demanding procedures.

## Transition to adult care

Transfer should include medical history, active problems, medication, communication preferences, decision-making support, key supporters, sensory needs, reasonable adjustments and pending follow-up. Teach the young person how to access prescriptions, appointments and urgent care using formats they can actually use.

## SECTION 13

# Adults, Older Adults and Life Transitions

*Maintain access across changing health, roles and support systems.*

- Autistic adults may enter healthcare with or without a formal diagnosis and with very different support networks.
- Ageing, menopause, chronic disease, bereavement, employment change or loss of a supporter can alter access needs.
- Clinicians should avoid assuming that longstanding coping strategies remain adequate after major life or health changes.

## Adult autonomy

Ask the adult directly about communication, privacy, supporters and decision-making. Do not assume a family member should speak for the person. Equally, do not exclude a chosen supporter when the person wants them involved.

## Older adults

New cognitive, functional, sensory or behavioral changes deserve clinical assessment and should not automatically be attributed to autism or ageing. Consider the person's lifelong baseline and current environment. Changes in housing, caregiving or routines can also affect presentation and self-management.

## Major transitions

- Moving from pediatric to adult services.
- Changing primary care clinician or specialist team.
- Hospital discharge to home, residential or community services.
- Pregnancy, parenthood or reproductive-health transitions.
- Ageing, bereavement or loss of a long-term supporter.
- Relocation, migration or disruption of established services.

## SECTION 14

# Inpatient Care, Surgery, Diagnostics and Discharge

*Make complex episodes of care coherent from admission to recovery.*

- Inpatient environments amplify sensory, communication and routine disruption.
- Perioperative and diagnostic pathways should identify access needs early, not at the point of procedure.
- Discharge is unsafe when instructions are inaccessible or responsibility for follow-up is unclear.

## Admission

- Record communication method, sensory needs, baseline behavior and distress signs.
- Clarify supporter presence and visiting arrangements within policy.
- Identify food, sleep, toileting, mobility and medication routines that materially affect care.
- Explain ward routines, likely interruptions and who to ask for help.

## Surgery and diagnostics

Where clinically possible, provide a pre-procedure sequence, explain fasting and medication instructions clearly, plan waiting, identify sensory triggers, preserve AAC access, and ensure recovery staff know the person's baseline. Use standard perioperative safety processes and individualized anesthesia assessment where required.

## Discharge standard

1. State the diagnosis or working diagnosis in accessible language.
2. List medication changes clearly and reconcile conflicting instructions.
3. Explain wound care, diet, activity, monitoring or device care as applicable.
4. Give explicit red flags and the service to contact.
5. State follow-up appointments, tests and who is responsible for arranging them.
6. Check understanding using the person's preferred communication method.

## SECTION 15

# Safeguarding, Privacy, Trauma-Informed Care and Quality Improvement

*Build services that are safe, respectful and accountable.*

- Autistic people may be vulnerable to abuse, neglect, discrimination, coercion or barriers to reporting concerns.
- Trauma-informed care avoids unnecessary re-exposure to fear, loss of control and sensory overwhelm.
- Quality improvement should include access outcomes and autistic people's experience, not only staff training completion.

## Safeguarding

Follow local safeguarding law and policy. Communicate privately when appropriate, use accessible questions, do not assume a supporter is always safe, and consider how communication differences may affect disclosure. Immediate risk requires appropriate escalation.

## Privacy and records

Access information should be visible to relevant care teams without exposing unnecessary personal detail. Record what helps, not stigmatizing labels. Distinguish clinical risk information from preferences. Obtain and document consent for sharing with supporters where required.

## Trauma-informed principles

- Explain before acting.
- Offer genuine choices when possible.
- Avoid unnecessary restraint or coercive language.
- Recognize that previous healthcare experiences may affect current behavior.
- Plan recovery and debrief after highly distressing care.

## Quality indicators

| Measure     | Question                                                                                |
|-------------|-----------------------------------------------------------------------------------------|
| Access      | Can autistic patients obtain appointments using accessible channels?                    |
| Adjustments | Are documented access needs visible and acted upon?                                     |
| Experience  | Do patients report being listened to and understood?                                    |
| Safety      | Are delays, restraint, repeated failed procedures or diagnostic overshadowing reviewed? |
| Continuity  | Does access information follow the patient across transfers and discharge?              |
| Capability  | Do staff know what to do, not merely that they completed training?                      |

# Practical Tools and Templates

The following tools are designed for local adaptation. They should be integrated with existing clinical records, governance and consent processes rather than creating parallel documentation that staff cannot access.

## Tool 1. Healthcare Access Passport

A one-page summary of how to make healthcare safer and more accessible for this person.

| Field                               | Complete with the patient / supporter |
|-------------------------------------|---------------------------------------|
| Preferred name & pronouns           |                                       |
| How I communicate best              |                                       |
| How I show yes / no / uncertainty   |                                       |
| AAC / communication device          |                                       |
| Sensory triggers                    |                                       |
| What helps me wait                  |                                       |
| How pain or illness may look for me |                                       |
| Touch / examination preferences     |                                       |
| What helps if I am overwhelmed      |                                       |
| Supporter role and consent          |                                       |
| Important medical risks             |                                       |
| Please avoid                        |                                       |

## Tool 2. Pre-Visit Information Sheet

Use before appointments or procedures to reduce uncertainty.

| Item                           | Information to provide |
|--------------------------------|------------------------|
| Purpose of visit               |                        |
| Location / arrival point       |                        |
| People likely to be present    |                        |
| Expected sequence              |                        |
| Likely duration                |                        |
| Possible waiting               |                        |
| Examination or procedure steps |                        |
| Sensory exposures              |                        |
| Preparation required           |                        |
| What to bring                  |                        |
| Adjustment contact route       |                        |

### Tool 3. Communication Profile

Document reliable communication for routine and high-stress situations.

| Area                     | Routine | When stressed / unwell |
|--------------------------|---------|------------------------|
| Receptive language       |         |                        |
| Expressive communication |         |                        |
| AAC / writing / visuals  |         |                        |
| Processing time          |         |                        |
| Yes / no reliability     |         |                        |
| Pain communication       |         |                        |
| Helpful wording          |         |                        |
| Avoid                    |         |                        |

### Tool 4. Sensory Access Plan

Identify environmental barriers and practical adjustments.

| Domain                 | Triggers / barriers | Helpful adjustment |
|------------------------|---------------------|--------------------|
| Noise                  |                     |                    |
| Lighting               |                     |                    |
| Crowding               |                     |                    |
| Touch                  |                     |                    |
| Smell                  |                     |                    |
| Temperature            |                     |                    |
| Movement / positioning |                     |                    |
| Equipment / alarms     |                     |                    |

## Tool 5. Waiting and Flow Plan

Reduce distress caused by delay and uncertainty.

| Question                                  | Plan |
|-------------------------------------------|------|
| Can the patient wait elsewhere?           |      |
| How will staff contact them?              |      |
| What delay threshold triggers an update?  |      |
| Can registration be completed in advance? |      |
| Can multiple tasks be coordinated?        |      |
| Who owns communication during delays?     |      |

## Tool 6. Pain and Illness Baseline

Record individualized indicators that may help future assessment.

| Baseline area                     | Usual presentation | Possible change when unwell |
|-----------------------------------|--------------------|-----------------------------|
| Communication                     |                    |                             |
| Movement / activity               |                    |                             |
| Sleep                             |                    |                             |
| Eating / drinking                 |                    |                             |
| Toileting                         |                    |                             |
| Facial / vocal signs              |                    |                             |
| Touch tolerance                   |                    |                             |
| Self-injury / repetitive movement |                    |                             |

## Tool 7. Procedure Preparation Plan

Plan a blood test, imaging study, dental procedure or similar intervention.

| Step                        | Plan |
|-----------------------------|------|
| Clinical objective          |      |
| What must happen            |      |
| What can be adapted         |      |
| How steps will be explained |      |
| Preferred order             |      |
| Positioning                 |      |
| Sensory adjustments         |      |
| Stop / pause signal         |      |
| Supporter role              |      |
| Recovery plan               |      |

## Tool 8. Emergency Quick Sheet

A concise handover tool for urgent settings.

| Critical item                      | Information |
|------------------------------------|-------------|
| Primary communication              |             |
| Baseline behavior / responsiveness |             |
| How distress may present           |             |
| Pain indicators                    |             |
| Sensory triggers                   |             |
| Effective de-escalation            |             |
| Supporter / decision support       |             |
| Major medical risks                |             |
| Do not assume                      |             |

### Tool 9. Medication Understanding Check

Confirm that the treatment plan is usable.

| Question                                                      | Patient / supporter response |
|---------------------------------------------------------------|------------------------------|
| What is the medicine for?                                     |                              |
| When and how will it be taken?                                |                              |
| What common problems should be watched for?                   |                              |
| What requires urgent help?                                    |                              |
| Are taste, swallowing, routine or packaging barriers present? |                              |
| Who will monitor and when?                                    |                              |

### Tool 10. Distress Prevention and Response Plan

Use for predictable overload, shutdown or crisis situations.

| Area                                      | Plan |
|-------------------------------------------|------|
| Early signs                               |      |
| Likely triggers                           |      |
| What helps                                |      |
| Communication when distressed             |      |
| Sensory reduction                         |      |
| People who help                           |      |
| What makes it worse                       |      |
| Clinical red flags requiring reassessment |      |
| Recovery needs                            |      |

## Tool 11. Inpatient Accessibility Plan

Use at admission and update during the stay.

| Domain                    | Plan |
|---------------------------|------|
| Communication             |      |
| Room / sensory needs      |      |
| Sleep and routines        |      |
| Food / hydration          |      |
| Toileting                 |      |
| Mobility                  |      |
| Medication administration |      |
| Observations / procedures |      |
| Supporter involvement     |      |
| Daily explanation of plan |      |

## Tool 12. Discharge Clarity Checklist

Check whether discharge information is understandable and actionable.

- ☐ Diagnosis / working diagnosis explained clearly.
- ☐ Medication changes reconciled and written down.
- ☐ Care tasks described step by step.
- ☐ Red flags and urgent contact route stated explicitly.
- ☐ Follow-up date / responsibility clear.
- ☐ Equipment, transport or community support arranged where relevant.
- ☐ Patient can access the information in their preferred format.
- ☐ Supporter involvement reflects the patient's wishes and legal requirements.

## Tool 13. Primary Care Annual Review Prompt

A non-diagnostic prompt for broad healthcare review; adapt to local policy and the person's age/risk profile.

| Domain                   | Questions / actions                                                      |
|--------------------------|--------------------------------------------------------------------------|
| Preventive care          | Are routine screening and immunization opportunities up to date?         |
| Dental / oral health     | Any access barriers or untreated symptoms?                               |
| Sleep                    | Any new or worsening sleep problem?                                      |
| Mental health            | Any change in mood, anxiety, functioning or safety?                      |
| Medication               | Is the current regimen understood, tolerated and monitored?              |
| Pain / physical symptoms | Any persistent or unexplained change in behavior or function?            |
| Communication            | Have access needs changed?                                               |
| Social context           | Any change in housing, support, work/education or safeguarding concerns? |

## Tool 14. Specialist Referral Handover

Transfer both clinical information and access information.

| Clinical                          | Access                              |
|-----------------------------------|-------------------------------------|
| Reason for referral               | Preferred communication             |
| Relevant history / investigations | Sensory needs                       |
| Current medication                | Waiting / scheduling adjustment     |
| Risks / red flags                 | Supporter role                      |
| Specific question for specialist  | What has worked / failed previously |

## Tool 15. Dental Visit Preparation Sheet

Support predictable, staged dental care.

| Element                               | Plan |
|---------------------------------------|------|
| Purpose of visit                      |      |
| Photos / familiarization before visit |      |
| Chair position and gradual recline    |      |
| Light / suction / sound sensitivity   |      |
| Touch and oral examination approach   |      |
| Stop signal                           |      |
| Breaks / staging                      |      |
| Home preparation                      |      |
| Follow-up / prevention plan           |      |

## Tool 16. Imaging Preparation Sheet

Plan for X-ray, ultrasound, CT, MRI or other imaging according to local clinical protocols.

| Element                                 | Plan |
|-----------------------------------------|------|
| What the patient will see / hear        |      |
| Clothing / metal / fasting requirements |      |
| Position and duration                   |      |
| Need to remain still                    |      |
| Noise protection if compatible          |      |
| Communication during scan               |      |
| Supporter presence policy               |      |
| Contingency if scan cannot be completed |      |

Tool 17. Pharmacy Accessibility Check

Use at dispensing or medicines counselling.

- ☐ Instructions are clear and consistent with the prescription.
- ☐ Written information is accessible.
- ☐ Swallowing, taste, texture or formulation issues have been identified.
- ☐ Packaging / opening barriers have been considered.
- ☐ Dosing schedule is realistic and understood.
- ☐ Patient knows whom to contact for side effects or missed doses.
- ☐ Any formulation change is clinically and pharmaceutically appropriate.

Tool 18. Mental Health Appointment Preparation

Clarify access needs before assessment or therapy.

| Area                                          | Plan |
|-----------------------------------------------|------|
| Preferred communication                       |      |
| Topics that are difficult to discuss verbally |      |
| Need for written questions / agenda           |      |
| Sensory environment                           |      |
| Supporter involvement                         |      |
| How distress / shutdown may look              |      |
| Safety / crisis information                   |      |
| Post-session recovery needs                   |      |

## Tool 19. Autism-Inclusive Clinic Self-Audit

A rapid service-level review.

| Standard                                | Yes | Partly | No | Action |
|-----------------------------------------|-----|--------|----|--------|
| Multiple booking / contact routes       |     |        |    |        |
| Adjustment needs recorded and visible   |     |        |    |        |
| Pre-visit information available         |     |        |    |        |
| Alternative waiting option              |     |        |    |        |
| Communication supports available        |     |        |    |        |
| Sensory adjustments possible            |     |        |    |        |
| Staff know distress response            |     |        |    |        |
| Access information included in handover |     |        |    |        |
| Autistic people involved in improvement |     |        |    |        |
| Access outcomes reviewed                |     |        |    |        |

## Tool 20. 30-Day Healthcare Service Action Plan

Convert the toolkit into immediate operational changes.

| Week | Priority                                                         | Owner | Evidence of completion |
|------|------------------------------------------------------------------|-------|------------------------|
| 1    | Map current patient journey and identify top 5 barriers          |       |                        |
| 2    | Implement adjustment-recording and pre-visit process             |       |                        |
| 3    | Introduce access passport / handover standard and staff briefing |       |                        |
| 4    | Test changes with patients, collect feedback and fix failures    |       |                        |

## Tool 21. 90-Day Inclusion Review Dashboard

Review whether changes improved real access and safety.

| Indicator                                                  | Baseline | 90-day result | Next action |
|------------------------------------------------------------|----------|---------------|-------------|
| Adjustment requests completed                              |          |               |             |
| Appointments abandoned / failed because of access barriers |          |               |             |
| Repeated procedures caused by access failure               |          |               |             |
| Patient experience: listened to / understood               |          |               |             |
| Documented access handovers completed                      |          |               |             |
| Distress / restraint / safety incidents reviewed           |          |               |             |
| Staff confidence in practical response                     |          |               |             |
| Autistic patient involvement in service improvement        |          |               |             |

# Implementation Roadmap

## Phase 1 - Establish the minimum standard

- Name an accountable clinical/service lead.
- Choose where access needs are recorded in the existing patient record.
- Define a simple adjustment-request route.
- Publish pre-visit information for high-volume services.
- Brief staff on communication, sensory access, diagnostic overshadowing and distress response.

## Phase 2 - Embed across the patient journey

- Link booking, reception, clinical, diagnostic, pharmacy, inpatient and discharge processes.
- Standardize handover of access information.
- Create alternative waiting and sensory options where feasible.
- Include autism accessibility in induction and simulation.
- Review emergency and restraint pathways for least-restrictive practice.

## Phase 3 - Measure and improve

- Collect autistic patient and family feedback in accessible formats.
- Review incidents involving delayed diagnosis, failed procedures, repeated attendance, distress or communication breakdown.
- Track adjustment completion and access failures.
- Include autistic people in redesign and governance.
- Publish improvement actions and remeasure.

### Implementation principle

Start with systems that affect every encounter: accessible contact, clear information, adjustment recording, communication support, waiting and handover. Training without operational change will not be enough.

## References and Further Reading

| Source                                                                   | Resource                                                                                                                                                                                                                                                                                                             |
|--------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| World Health Organization (2025)                                         | Autism fact sheet. Updated 17 September 2025.<br><a href="https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders">https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders</a>                                                                                                 |
| NICE CG142                                                               | Autism spectrum disorder in adults: diagnosis and management. Last updated 14 June 2021.<br><a href="https://www.nice.org.uk/guidance/cg142">https://www.nice.org.uk/guidance/cg142</a>                                                                                                                              |
| NICE CG170                                                               | Autism spectrum disorder in under 19s: support and management. Last updated 14 June 2021.<br><a href="https://www.nice.org.uk/guidance/cg170">https://www.nice.org.uk/guidance/cg170</a>                                                                                                                             |
| NICE CG128                                                               | Autism spectrum disorder in under 19s: recognition, referral and diagnosis. <a href="https://www.nice.org.uk/guidance/cg128">https://www.nice.org.uk/guidance/cg128</a>                                                                                                                                              |
| United Nations                                                           | Convention on the Rights of Persons with Disabilities, Article 25 - Health.<br><a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html</a> |
| AASPIRE / Academic Autism Spectrum Partnership in Research and Education | Healthcare Toolkit for Autistic Adults.<br><a href="https://autismandhealth.org">https://autismandhealth.org</a>                                                                                                                                                                                                     |
| American Academy of Pediatrics (2026)                                    | Autism in Pediatric Practice: A Clinician's Guide. AAP Books.                                                                                                                                                                                                                                                        |
| World Health Organization and UNICEF                                     | Global report on children with developmental disabilities: From the margins to the mainstream.                                                                                                                                                                                                                       |

### Evidence use note

This toolkit emphasizes healthcare accessibility and service design. It does not attempt to reproduce disease-specific clinical guidelines. Services should use current national or local guidance for diagnosis, prescribing, emergency care, surgery, mental health, safeguarding, infection control, restraint and all other regulated clinical activities.

## About GARC

Global Autism Research Center (GARC) develops research, evidence resources, practical toolkits, frameworks, partnerships and knowledge products intended to strengthen autism-related policy, practice and institutional capacity internationally.

### GARC Practical Toolkits Series

The series translates evidence and rights-based principles into practical resources for schools, families, educators, early-years settings, universities, workplaces, healthcare systems and community institutions.

### Series publications completed

- 01 - School Community Autism Toolkit
- 02 - Family & Caregiver Autism Toolkit
- 03 - Educator Autism Toolkit
- 04 - Early Years Autism Toolkit
- 05 - University & Higher Education Autism Toolkit
- 06 - Workplace & Employer Autism Toolkit
- 07 - Healthcare Professional Autism Toolkit

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