

AUTISM SERVICE READINESS

From Fragmented Support to Coordinated Systems

A practical seven-domain framework for governments, institutions and service systems seeking more accessible, coordinated and measurable autism support.

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PUBLICATION STATUS: Evidence brief / institutional working publication. This is not clinical guidance, a diagnostic tool or a country ranking. It translates current public evidence and the GARC research agenda into a service-system readiness framework for institutional discussion and pilot testing.

Executive summary

Autism is a diverse group of neurodevelopmental conditions, and the abilities and support needs of autistic people vary across individuals and over time. The World Health Organization estimates that about 1 in 127 people globally had autism in 2021 and emphasises that care should be accompanied by community and societal action for accessibility, inclusion and support. This creates a system challenge, not only a clinical one: institutions need pathways that are understandable, coordinated, inclusive and measurable.

- Service readiness should be assessed across the whole pathway - governance, access, workforce, inclusion, family navigation, data and digital systems - rather than by counting isolated programmes.
- No single model fits every jurisdiction. The framework is designed for adaptation to national law, service configuration, culture, available workforce and lived experience.
- The immediate goal is not perfection. It is to identify system gaps, assign accountable owners and create a staged improvement plan with measurable indicators.

CORE PROPOSITION: A service system is ready when people can find the pathway, reach appropriate support, experience coordinated transitions, participate in education and work, and see the system improve through trustworthy data and accountable governance.

WHY SERVICE READINESS MATTERS

Autism support is a pathway, not a single intervention

1. Diversity of needs requires adaptable systems

WHO highlights that autistic people have varied abilities and needs, some live independently while others require substantial lifelong care and support. A readiness model therefore needs to accommodate different ages, communication profiles, co-occurring needs and levels of support without forcing people into one standard pathway.

2. Inclusion is part of system quality

The Convention on the Rights of Persons with Disabilities recognises inclusive education and the right to work on an equal basis with others. For autism service systems, this means readiness extends beyond diagnosis and health services to education, employment, community participation and accessible public services.

3. Fragmentation creates navigation costs

When health, education, disability, social care and employment systems operate independently, families and autistic people can become the de facto coordinators. A mature system defines entry points, referral rules, transition ownership and feedback loops across organisations.

4. Data must support improvement, not only reporting

Readiness requires a minimum set of indicators that can answer practical questions: who is being reached, where delays occur, whether people complete referrals, how transitions perform and whether outcomes differ across population groups. Data governance and privacy controls are prerequisites for any person-level data use.

THE SEVEN READINESS DOMAINS

A system view for assessment and improvement

Domain	What readiness means	Illustrative evidence
1. Governance & Rights	Clear mandate, cross-agency accountability, rights-based design, escalation and review mechanisms.	Named governance owner; cross-sector steering; documented accountability; rights and accessibility checks.
2. Access & Navigation	Understandable entry points, referral criteria, navigation support and continuity across transitions.	Single public pathway map; wait-time monitoring; referral completion; transition protocol.
3. Workforce Capability	Role clarity, competence development, supervision and multi-disciplinary collaboration.	Competency framework; role-based learning; supervision standards; capacity analysis.
4. Education, Work & Community Inclusion	Institutional accommodations and pathways that support participation across the lifespan.	Inclusive education controls; transition planning; employer guidance; accessibility measures.
5. Family & Lived-Experience Partnership	Structured mechanisms to incorporate autistic people and families in design, review and improvement.	Accessible engagement; paid/recognised participation where appropriate; feedback response log.
6. Data, Indicators & Outcomes	Minimum datasets, definitions, quality controls, dashboards and outcome measures.	Data dictionary; governance owner; indicator set; quality checks; equity stratification.
7. Digital & AI Governance	Technology used to improve access and operations with privacy, safety, transparency and human oversight.	Use-case register; data protection review; human oversight; model/vendor assessment; audit trail.

IMPORTANT: The framework is intentionally non-ranking. It supports internal maturity assessment and improvement planning; it should not be used to publish league tables without validated methods, comparable data and appropriate governance.

A FOUR-LEVEL MATURITY MODEL

Use maturity to sequence action, not to label institutions

Maturity	Typical condition	Priority action
Level 1 - Fragmented	Services exist, but pathways, roles and data are inconsistent or difficult to navigate.	Map the current system and remove the most critical access and safety gaps.
Level 2 - Defined	Core pathways, roles and procedures are documented, but implementation and measurement vary.	Standardise high-priority processes and assign owners.
Level 3 - Integrated	Cross-agency pathways, indicators and improvement routines operate consistently.	Strengthen data quality, transitions, lived-experience review and outcome measurement.
Level 4 - Learning System	The system uses timely evidence, outcomes and feedback to adapt services and policy.	Embed continuous improvement, comparative learning and responsible innovation.

Suggested assessment method

1. Define scope: national, regional, provider network or institutional system.
2. Collect documentary evidence and pathway data before scoring.
3. Include autistic people, families, practitioners and system owners in interpretation.
4. Rate each domain using explicit evidence and record uncertainty.
5. Convert findings into 90-day, 6-month and 12-month actions with named owners.
6. Reassess after implementation using the same definitions and evidence rules.

A 180-DAY ACTIVATION ROADMAP

A practical starting sequence

Window	Focus	Key outputs
Days 0-30	Baseline & governance	Confirm scope; appoint sponsor; map services, entry points and transitions; define evidence sources; establish engagement safeguards.
Days 31-60	Pathway & data design	Agree pathway map, referral logic, minimum indicators, data dictionary and initial dashboard specification.
Days 61-90	Priority controls	Implement two to four high-impact controls such as navigation guidance, transition protocol, wait-time monitoring or accessible feedback.
Days 91-120	Capability & inclusion	Launch role-based workforce development and inclusion controls for education/employment/community settings.
Days 121-150	Review & learn	Review early performance, lived-experience feedback, data quality and unintended barriers.
Days 151-180	Scale plan	Approve next-cycle priorities, resource plan, research questions and improvement targets.

Minimum dashboard

- Access: entry-point volume, referral completion, waiting times and drop-off points.
- Continuity: transition completion between child/adult, education/employment and service settings.
- Experience: accessible feedback, navigation confidence and unresolved complaints/barriers.
- Inclusion: participation and accommodation indicators where data are lawful and meaningful.
- Quality: pathway adherence, data completeness, review frequency and corrective-action closure.

RESEARCH AGENDA & NEXT STEP

How GARC will develop the framework

Priority research directions

- Validate the seven-domain framework through expert, institutional and lived-experience review.
- Develop a Gulf Autism Service Readiness Framework without country ranking in version 1.
- Produce a family navigation and care coordination evidence map.
- Develop implementation tools for inclusive education and transition to employment.
- Design a minimum data set and governance specification for autism service systems before any patient-record use.

For institutions

A readiness assessment should begin with a defined decision question, scope and evidence set. GARC can support desk synthesis, system mapping, indicator design, governance review, expert/lived-experience engagement and an implementation roadmap. Any activity involving personal data, research participants or sensitive records requires a separate ethics and data-protection decision.

GARC POSITION: Global Autism Research Center is a research and systems institution. It does not provide individual diagnosis or treatment and this brief is not medical advice.

References & evidence base

1. **World Health Organization. Autism fact sheet, 17 September 2025.** WHO reports a global 2021 estimate of about 1 in 127 and emphasises diversity of needs, inclusion and community support. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>
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3. **United Nations Convention on the Rights of Persons with Disabilities - Article 24: Education.** Right to inclusive education. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-%20disabilities/article-24-education.html>
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5. **GARC Annual Research Agenda 2026-2027.** Internal GARC agenda used to define the initial applied research sequence. <https://globalautismresearch.org.uk/>