

Wait Times and Processes for Autism Diagnostic Evaluations: A First Report Survey of Autism Centers in the U.S.

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BACKGROUND

Despite mounting evidence that early autism diagnosis and intervention can improve long-term outcomes and quality of life,¹ significant diagnostic delays with pronounced health disparities persist.² While reliable autism diagnosis is possible as early as 18 months,³ in the U.S. the average age of diagnosis remains above four years.⁴ Specialists typically conduct the vast majority of autism evaluations.⁵ Recent workforce surveys, however, have highlighted workforce shortages⁶ and continued rise in the overall prevalence of autism among 8-year-olds, now estimated at 1:36.⁴ Data is urgently needed to quantify the extent of the resulting waitlist crisis for autism evaluations. Insights focused on current autism specialty center wait times and processes could help to direct future healthcare resources, and support development of policies and initiatives that reduce barriers to timely diagnosis and treatment initiation.

The **objectives** of this first-of-its-kind observational, cross-sectional U.S. study were to:

- Quantify wait times for autism assessments across U.S. autism specialty/diagnostic centers
- Identify steps and time involved in obtaining an autism diagnosis including intake, screening and diagnostic procedures, type of clinician conducting the assessment and types of insurance accepted
- Capture barriers to timely evaluations and specialist proposed suggestions for practice improvement

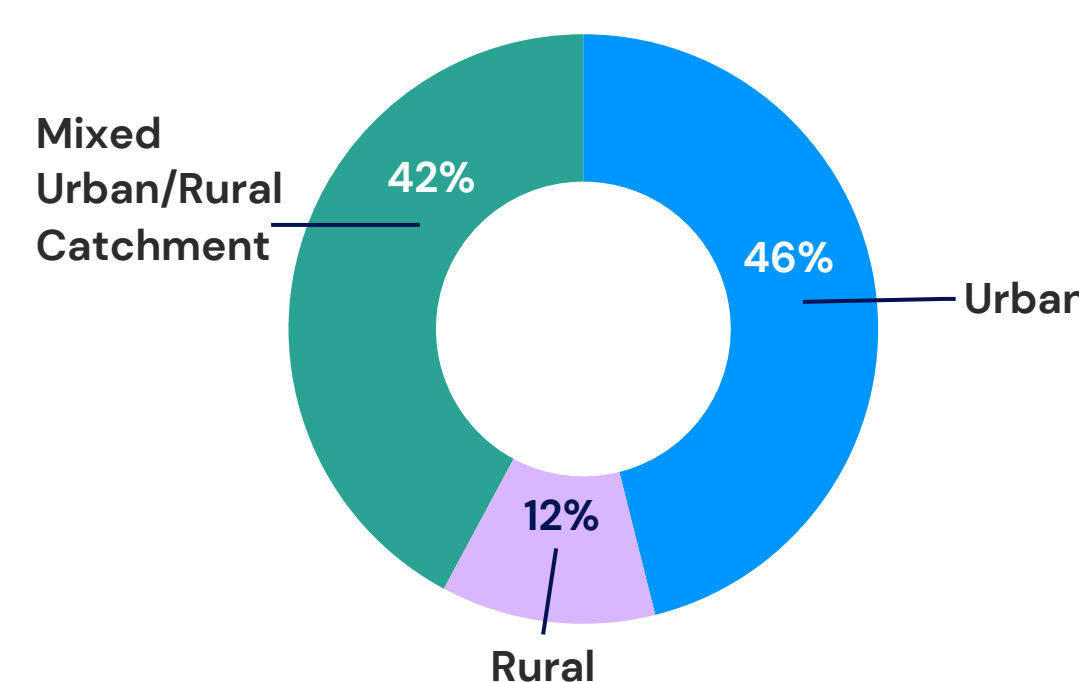
METHODS

Both multi-practitioner and sole practitioner specialty centers conducting autism evaluations were identified through a combination of web searches and claims data analysis. A brief anonymous, English only, online survey was then distributed to identified autism specialty centers across all U.S. states and the District of Columbia (n=1,004) via email. Responses were collected November 2022 through end of March 2023. The study received an IRB exemption from Advarra (Pro00067552).

RESULTS

Description of respondent centers: 111 centers responded (11.1% response rate). Of these, 61.76% were multi-practitioner diagnostic centers. The remaining 38.24% were sole practitioner centers.

Geographic designation: Responses were received from 38 unique states: Highest responses were received from CO (9%); MA (6%); PA, UT, TX, CA (all 5%); AZ, OH and VA (all 4%); NJ, RI, MS, NY, TN (all 3%).



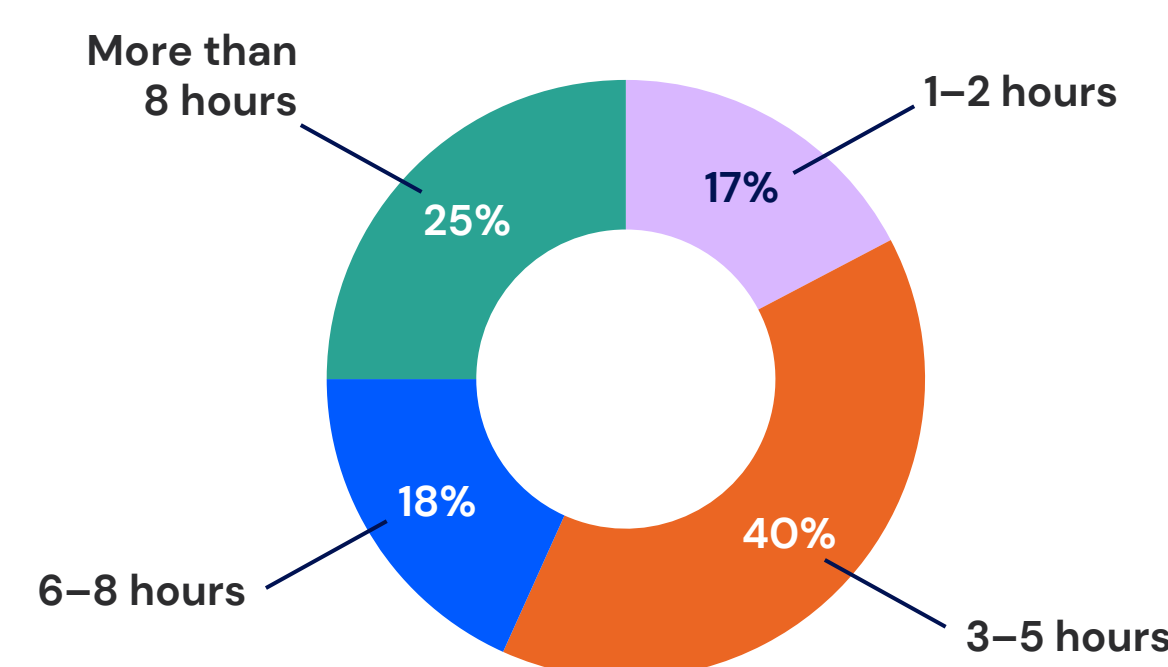
Type of Insurance Accepted	% of centers accepting
Private Pay (out-of-pocket)	84%
Private/commercial	65%
Medicaid	56%
Tricare (military)	39%
Other	16%

Total number of respondent centers = 100

Wait Times for Autism Evaluations	%
Waitlist so impacted – not currently accepting referrals	3%
More than one year	13%
7–11 months	15%
4–6 months	31%
1–3 months	25%
0–4 weeks	14%

Total number of respondent centers = 111

Hours taken to complete each individual autism evaluation:



Assessment tools and processes:

There was wide variability in reported tools and assessment processes used across centers. Some centers did not use any formal autism diagnostic tools or screeners beyond the DSM-5 criteria, others variously reported using STAT, CARS-2, M-CHAT, ADOS-2, ADI-R, SRS-2, GARS, RAADS-R, SCQ, GADS, MIGDAS, ASRS, RITA-T, and Tele-ASD Peds. Tools used to assess adaptive, cognitive, and developmental domains included Vineland, Developmental Profile IV, BASC, ABAS-3, Bayley-4, BRIEF, SPM-2, NEPSY-TOM, WISC-V, WNV, and PAI. 69.61% of centers (n=71) required in-person in-clinic evaluations; 1.96% (n=2) of centers reported offering telehealth autism evaluations; 19.61% (n=20) offered both in-person and telehealth options; 8.82% (n=9) described other delivery models.

Professional qualifications of specialists:

Most centers had psychologists conducting autism assessments (94.06%, n=95). 20.79% (n=21) also had developmental pediatricians, 13.86% had psychiatrists while 12.87% had nurse practitioners and 11.88% had neurologists. Other practitioner types were involved in 15.84% of centers. These included social workers, behavioral analysts, occupational therapists and speech language pathologists.

Specialist identified barriers to timely autism evaluations included:

- Workforce shortages 69% (n=70)
- Large volume of referrals 61% (n=63)
- Time required to write report and fulfill payor testing documentation requirements 54% (n=55)
- Time required to conduct the evaluation 37% (n=38)
- Inadequate reimbursement 30% (n=30)

“We take over 1000 calls from the community every year, and the most common request is for autism assessments.”

“Our clinic loses money on every autism assessment due to low reimbursement rates.”

“Extremely low reimbursement rates from insurance means we cannot afford to accept insurance at this time, which means that only families that can afford to pay out of pocket can access our practice.”

Discussion

Findings from this first-of-its-kind survey highlight **unacceptably long wait times** for autism evaluations for many children: Nearly two-thirds of centers (61.26%) had wait times longer than 4 months, with 15.32% reporting waits of over one year, or waitlists that were so impacted they were no longer accepting new referrals. Delays to evaluation mean many children may miss the opportunity for early intervention in the critical early neurodevelopmental window where therapies have the greatest lifechanging impact.

Multiple barriers to timely evaluation were identified, including **extreme length of assessment processes and heavy documentation burden** (No respondent centers were able to complete an individual assessment in under one hour, and in a quarter of cases each evaluation was reported to take more than 8 hours). Other access barriers included **burdensome reimbursement processes** or inadequate reimbursement to incentivize service provision. Access disparities and lack of reimbursement may hit already underserved communities such as Medicaid families the hardest, with nearly half (44%; n=56) of centers reporting that they did not accept Medicaid patients.

Study findings highlight that **there is no current standard of care in the diagnoses of autism in the U.S.** In some centers no formal diagnostic tools or screeners beyond the DSM-5 criteria were used, while others required multiple screening and diagnostic tools and additional adaptive, cognitive, and developmental domain specific tests. Evaluations ranged from 1–2 hours in some centers to over 8 hours in others, while initial wait times varied from less than 4 weeks to well over one year.

Survey findings highlight the need to standardize, equitize, and streamline evaluation processes through policy change to enable early, equitable and accurate autism diagnosis and treatment for all families, irrespective of insurance type or location. Strategies should be explored to expand the pool of autism providers to include primary care and reduce hurdles to reimbursement. Length of assessment and documentation burden could also be reduced through endorsement of more efficient FDA-authorized diagnostic tools.⁷

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