RESEARCH LETTER

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# Demographic and socioeconomic characteristics of patients diagnosed with autism through the Rapid Interactive screening Test for Autism in Toddlers

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Despite improvements in access and early diagnosis of autism spectrum disorder (ASD), age at initial diagnosis continues to occur closer to 4 years of age.[1] The US Centers for Disease Control and Prevention recently published data that shows a trend in improved access and identification for children from black or Latino groups.[2] However, there is still a significant discrepancy in access to care for children and families from culturally and linguistically diverse (CLD) backgrounds, and from underserved areas. Early identification and appropriate interventions are key for attaining optimal outcomes.[3] Deferred identification in general results in delayed intervention access and increases the risk for prolonged experiences in ineffective environments for a child's intellectual, emotional, and social development. Deleterious effects are amplified in children from immigrant and historically marginalized communities.[4,5] Under-resourced communities are particularly at risk of delayed ASD diagnosis as they have the least amount of access to developmental screening, diagnoses, and services. This context threatens young children's neurodevelopment and the well-being of their mental health.[6]

There is a shortage of appropriate and valid ASD screening measures that can be used in different populations, and that are accessible and easily administered by community practitioners.[7] Furthermore, engaging CLD families who are at risk and gaining their trust can be challenging.[8] This can lead to missing windows of opportunity to apply effective intervention early in their child's development.

In parallel, the American Academy of Pediatrics promotes early screening and diagnosis of neurodevelopmental disorders and ASD in primary care (PC) and early intervention (EI) providers;[9] however, this practice is inconsistent.[10] Even if screening occurs, there continue to be several barriers to getting the child and family to their appropriate diagnostic evaluation and services. Barriers to services can be physical, such as location and transportation, but these barriers can also be attributed to cultural or social factors.[11] Building capacity and skills in the early identification of neurodevelopmental disorders and ASD and collaborating with early childhood community providers in underserved areas are essential in improving the early identification of ASD.[12]

There are screening models that have been evaluated in community practice to increase access to early identification of ASD, such as the TELE-ASD Peds, and have yielded good results.[13] However, these models can also be limited to families who do not have consistent access to technology and may be unfamiliar with virtual evaluations. The importance of community models continues to be discussed to reduce barriers to accessing an autism evaluation and diagnosis.[14] Models such as enhancing post-graduate

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training for clinicians and integrating teachings on autism and early autism detection, as well as training PC providers to equip them to provide developmental evaluations and provide autism diagnosis, are discussed as strategies to mitigate limiting factors to a diagnosis.[15] Accessibility to providers and tools to aid in screening and diagnosis, and collaborations between providers in the community are paramount in providing equitable access to populations and families that need access to care.[7]

The Rapid Interactive screening Test for Autism in Toddlers (RITA-T) model,[16] an interactive ASD screening model that we developed, relies on the training of early childhood providers, namely EI providers, in addition to PC providers, to screen for autism, and start a conversation with the family about concerns for autism and possible referrals and evaluations. In addition, the RITA-T is brief, easy to learn, and integrated in their home or center visits, or in clinic settings. Our goal here is to compare demographic and socioeconomic characteristics between the toddlers diagnosed with ASD with the RITA-T screening in the community and the toddlers diagnosed with ASD without the RITA-T screening and examine whether the RITA-T model is successful in improving the early identification of high-risk toddlers from underserved areas.

The RITA-T is an interactive screening measure that includes nine interactive activities. The RITA-T evaluates the developmental constructs delayed in early autism such as joint attention, shared enjoyment, and social awareness. The RITA-T is easy to train reliably within 3 hours and can be administered and scored within 20 minutes. It is inexpensive to acquire and relies very little on the child's language. It is validated for children 18–36 months old, and cut-off scores have been established and replicated with consistency across different settings and studies, and with excellent psychometrics.[16–18] We have previously published on the RITA-T as the second-level screening tool in a two-level screening model and its integration in PC and in EI.[16]

Over a period of 14 months, (April 2022–June 2023), we continued conducting training for EI community providers and supported several PC practices to establish RITA-T screening models within their practice. We trained 2–4 providers on average within 11 PC centers including private practices, community health centers, and a hospital-based PC center in the state of Massachusetts (MA) in the US. In addition to the 11 PC centers, we also trained 44 EI programs on this screening measure over the course of 3 years. Each of the participating providers trained reliably on the RITA-T over the course of 3 hours. The reliability of the RITA-T was monitored and attained at the end of the training. As part of an initiative through the MA Act Early Campaign and with the MA Department of Public Health, EI programs across the state were offered training at no cost to them. As more EI programs were trained and referred young children for evaluations, the PC providers gained more awareness about this model and sought to be trained as well. For this study, the referring trained EI programs were from all areas in the state of MA. We supported PC providers in establishing a screening system within their practice for screening those at risk utilizing the RITA-T, and this included the Modified CHecklist for Autism in Toddlers, revised with follow-up (MCHAT-R/F)[19] as an initial screening, then followed by the RITA-T. We established an Autism-R diagnostic clinic in this urban tertiary care center, where the PC and EI providers referred children for a diagnostic evaluation of ASD after screening with the RITA-T. We created material to streamline the referrals to this diagnostic clinic that included a document completed by the PC or the EI provider on their concerns that initiated the referral, the MCHAT-R/F, and the RITA-T scoring sheet that included comprehensive qualitative observations that the provider would note during their administration of this measure. This urban tertiary care center also had an established standard Autism-S diagnostic clinic and received referrals from providers that were outside of the discussed screening model but were close to the urban center. The PC centers and EI programs referring to the Autism-S diagnostic clinic were not trained on the RITA-T. Families were also referred by other healthcare providers (psychologists, psychiatrists, or internal referrals) to this clinic.

Both diagnostic clinics in this tertiary care center took all insurance. The Autism-S clinic requested that a parent questionnaire be completed and returned before an appointment was scheduled, whereas the Autism-R clinic accepted questionnaires completed by the child's EI or PC provider, in addition to the RITA-T scoring sheet and the MCHAT-R scores, and did not require parents to complete a questionnaire before they were scheduled.

We retrospectively reviewed the charts of toddlers 18–36 months old, who were referred for a concern of ASD through the RITA-T screening model, and a sample of those referred through the standard traditional referral route within the same period of time. Typically, providers evaluated 1–2 new referrals each week from the standard route, and that stayed consistent throughout the study period. We collected demographic and socioeconomic information, including gender, race, ethnicity, age, and their wait time from referral to final diagnosis, as well as family income, miles traveled to the clinic for their diagnostic appointment, and approximate time traveled to the clinic that was derived from their zip code. We received approval for this project (IRB-P00043040) from the Boston Children's Hospital Institutional Review Board to complete this review.

The area of deprivation index (ADI) is a metric that uses data to geographically categorize areas that are socioeconomically disadvantaged by analyzing factors such as

employment, income, and education, for example.[20,21] This information is valuable in further understanding disparities in health delivery and access that disadvantaged neighborhoods and their populations often face. This can offer insight into patient populations from historically marginalized communities and identify their needs to help address barriers to access to care. In this study, we collected information on ADI in two forms: state decile ADI scores ranging from 1 to 10 and national percentile ADI scores ranging from 1 to 100.

All toddlers in either an autism diagnostic clinic (RITA-T screened or traditional referral) were evaluated over one 90-minute visit. Staff included a neurodevelopmental pediatrician and/or neurology nurse practitioner. Often, one diagnostic evaluation visit was sufficient and almost all the evaluations were done in person. After the initial diagnostic visit, families were connected with the center's autism resource specialist to review resources in their area. Diagnostic evaluations included the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) interview/checklist,[22] Autism Diagnostic Observation Schedule Second Edition[23] toddler, module 1 or module 2 as indicated clinically. Diagnostic evaluation visits also included a checklist based on the DSM-5 developed by this team titled the Early Autism Screening Inventory[24] and the Childhood Autism Rating Scale Second Edition.[25]

In this article, we compared two groups: (1) the toddlers diagnosed with ASD through the Autism-R clinic and previously screened by the RITA-T, and (2) the toddlers diagnosed with ASD only through the standard Autism-S clinic. We examined the differences in their demographic and socioeconomic characteristics.

We compared demographic and socioeconomic characteristics between the ASD toddlers diagnosed with the RITA-T screening and those without the RITA-T screening. We reported counts and percentages for categorical variables, and for continuous variables, we calculated medians and interquartile ranges. We performed Fisher's exact test to compare categorical counts between groups and performed the Mann-Whitney *U*-test to compare continuous variables. An $\alpha$- level of 0.05 was used to determine statistical significance.

Over 14 months, 394 ASD toddlers were identified and included in our comparison. Out of the 394 evaluated, 323 were screened initially by the RITA-T model, and 71 were referred through the regular standard diagnostic clinic (Table 1). One hundred and eight PC providers, including providers from pediatrics and family medicine, sent referrals to the Autism-R diagnostic clinic. EI providers sent 286 referrals, and they would initiate the referral and inform the child's PC provider.

We compared demographic and socioeconomic characteristics for two groups of toddlers: those referred after being screened by the RITA-T, and those referred without an initial screening (Table 1). Gender and age were comparable in both groups evaluated. The toddlers referred through the RITA-T system waited less to be evaluated than those in the regular diagnostic clinic (186 [119, 240] *vs.* 119 [78, 154], $P < 0.001$). The toddlers referred through the RITA-T system traveled further to the clinic (30.40 [14.45, 44.80] *vs.* 40.00 [31.90, 48.60], $P < 0.001$), showing a statistically significant difference. They also came from different racial backgrounds ($P = 0.025$) with the toddlers not screened by the RITA-T system, although the ethnicity distribution of the two groups was not significantly different ($P = 0.651$). Household income of the toddlers referred through the RITA-T system was significantly lower than those not screened by the RITA-T system (66.55 [50.80, 78.69] *vs.* 53.80 [45.15, 73.57], $P = 0.019$). The state decile ADI score (Figure 1)[26] and national percentile ADI score were also compared between the two groups, and a significant difference was discovered in both scores (both $P < 0.001$). The toddlers referred through the RITA-T system came from neighborhoods with more disadvantaged socioeconomic conditions compared to those seen in the regular diagnostic clinic (state decile ADI score: 5.0 [4.0, 7.5] *vs.* 8.0 [6.0, 9.0], $P < 0.001$; national percentile ADI score: 25 [17, 35] *vs.* 33 [22, 46], $P < 0.001$).

We completed this retrospective observational study to compare the demographic and socioeconomic characteristics of the patients with a RITA-T community screening and referral model to a traditional model and investigated whether the RITA-T model improved early identification from underserved areas and diverse racial groups. A total of 11 PC practices were trained on integrating the RITA-T screening model in their settings, and completed referrals to the clinic, in addition to the 213 referrals sent through EI programs. The toddlers referred through the RITA-T model were more likely from areas with increased ADI classifications as categorized by state decile ADI scores or national percentile ADI scores. The patients referred through the RITA-T model also traveled further for their evaluation and came from different racial backgrounds.

There are a few discussion points that are important to address:

1. In this particular cohort, there is an unequal distribution of the number of those screened with RITA-T *vs.* those from the standard pathway. This is explained by the fact that this sample is drawn from a clinic that was originally based on the standard model (i.e., 1–2 new evaluations per week), which remained constant throughout the 14 months of this study. As the RITA-T referrals started to come through, 4–6 evaluations per

**TABLE 1** Summary statistics and comparison of demographic and socioeconomic characteristics for two groups of toddlers diagnosed with autism spectrum disorder: (1) those referred after being screened by the RITA-T model and (2) those referred without an initial RITA-T screening

| Characteristics | Without RITA-T screening ($n = 71$) | With RITA-T screening ($n = 323$) | *P*-value |
|---|---|---|---|
| Gender | | | 0.563 |
| Female | 18 (25.4) | 95 (29.4) | |
| Male | 53 (74.6) | 228 (70.6) | |
| Age (months) | 31 (27, 34) | 31 (27, 35) | 0.555 |
| Race | | | 0.025 |
| American Indian or Alaska Native | 1 (1.4) | 2 (0.6) | |
| Asian | 4 (5.6) | 29 (9.0) | |
| Black or African American | 22 (31.0) | 52 (16.1) | |
| More than one race | 0 (0) | 5 (1.5) | |
| Native Hawaiian or other Pacific Islander | 1 (1.4) | 0 (0) | |
| Unknown | 2 (2.8) | 21 (6.5) | |
| White | 41 (57.7) | 214 (66.3) | |
| Ethnicity | | | 0.651 |
| Hispanic or Latino | 19 (26.8) | 83 (25.7) | |
| Not Hispanic or Latino | 50 (70.4) | 221 (68.4) | |
| Unknown | 2 (2.8) | 19 (5.9) | |
| Travel distance (miles) | 30.40 (14.45, 44.80) | 40 (31.90, 48.60) | <0.001 |
| Travel time (minutes) | 45 (30, 60) | 60 (60, 60) | <0.001 |
| Household income (dollars in thousands) | 66.55 (50.80, 78.69) | 53.80 (45.15, 73.57) | 0.019 |
| Wait time from referral to appointment in days | 186 (119, 241) | 119 (78, 154) | <0.001 |
| State decile ADI score | 5.0 (4.0, 7.5) | 8.0 (6.0, 9.0) | <0.001 |
| National percentile ADI score | 25 (17, 35) | 33 (22, 46) | <0.001 |

Data are shown as *n* (%) or median (Q1, Q3).
Abbreviations: ADI, area of deprivation index; RITA-T, Rapid Interactive screening Test for Autism in Toddlers.

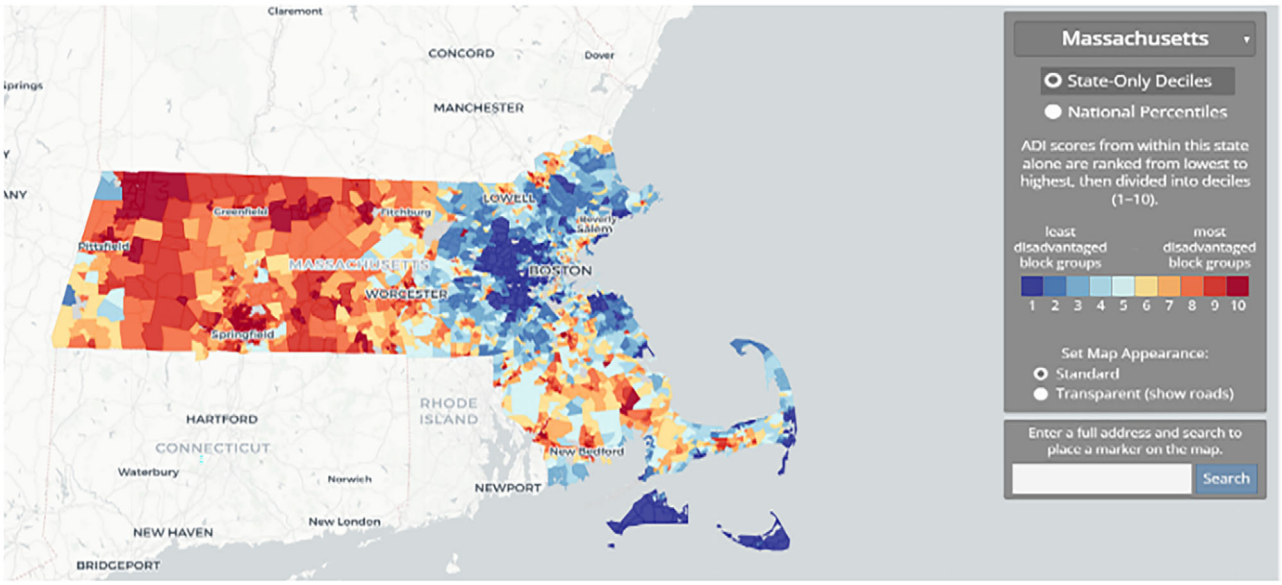


**FIGURE 1** The state of Massachusetts's area deprivation index (ADI) scores by state deciles.

week were added and were for the Autism-R clinic. The Autism-R clinic was also a teaching clinic and program for nurse practitioners, and other early childhood providers.
2. Interestingly, age at evaluation was similarly distributed and was not different between groups, even though those seen through the regular pathway waited longer to be seen. In general, the patients referred through the standard pathway were displaying clear signs of autism, or came from different racial backgrounds, and their referral had been initiated earlier, but they waited longer to be seen which led to their age at evaluation being similar to those seen through the RITA-T pathway. Despite their PC referring them appropriately, they ended up waiting a long time to be seen through the standard pathway.
3. The referrals from EI programs were almost double those from PC centers. As previously mentioned, the EI programs that were trained were from all areas across the state of Massachusetts. This would explain that toddlers evaluated were geographically further out, as opposed to the referrals in the non-RITA-T group that were more often initiated by their PC and were thus located closer to the urban center.
4. In the Autism-R clinic, families were scheduled after receiving the scoring sheets for the RITA-T, MCHAT-R/F, and EI and PC questionnaires. A parent-completed questionnaire was not a requirement as it was for those referred through the standard pathway, which may be another reason that those children accessed diagnostic services more easily. Parents may have difficulties completing long questionnaires and returning them, especially if they do not speak or read English, or if they are not familiar with the questions asked.

Limitations of this study:

1. Unbalanced group size: this was an observational study and focused on the RITA-T model thus explaining the larger number of children screened on the RITA-T. However, the group of those referred through the traditional pathway was typical of what one to two providers would see within that same amount of time. As we seek the generalization of this model, formal recruitment and balanced group sizes may be considered in future studies.
2. Race and Ethnicity collections: we reviewed the percentage of toddlers with race or ethnicity categorizations of "unknown" in the RITA-T referred group. As this study was completed retrospectively, race and ethnicity categorizations were noted as they were inputted through the electronic chart system.[27,28] Some systems list ethnicity as either Hispanic or Latino or Not Hispanic or Latino, which was a categorization separate from race. Choices for entering race and ethnicity were limited to basic categories and did not have choices representative of all the patients who were being evaluated. Additionally, there were limitations in how this information was collected from families as well. Families would often be asked about their racial/ethnic classifications as they were checking into their appointments. However, this reporting system was not ideal, as parents were often accompanied by their children and would also be completing paperwork including insurance papers and other documentation required for the visit, and would abstain from answering or not know the answer.

Despite the discussed limitations, the RITA-T screening model improved wait time and access to diagnostic services. PC and EI providers who participated in this model reported ease of training and integration in their programs. Training PC and EI providers on the discussed screening model can significantly strengthen community partnerships and help address disparities and healthcare access. Additionally, the RITA-T screening model can reduce the amount of paperwork families have to complete before an evaluation, which may cause them further delays regardless of how early they were referred. Further training and the generalization of this model to other settings is needed.

## ETHICAL APPROVAL

The ethical approval was obtained from the Boston Children's Hospital Institutional Review Board (IBR-P00043040).

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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