

Scoping Review of Autism Level One Screeners Created or Adapted for Diverse Populations in the United States

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Introduction

- At present, Level 1 screening tools are frequently used by pediatricians, early education teachers, and early intervention providers to identify toddlers with an increased likelihood of meeting criteria for an autism spectrum disorder (ASD).^{1,2,3,4}
- We define Level 1 screening tools as behavioral, parent report, measures developed for use within communities to identify children at-higher-likelihood for meeting criteria for various developmental disorders, including ASD.⁵
- Level 1 screening tools used in community settings are often employed as one strategy to: decrease inequity in detection/diagnosis, decrease age of first ASD diagnosis, and increase access to autism specific healthcare services and early intervention, including free early intervention services provided through IDEA Part C.⁶
- Participation in early intervention services has been associated with developmental outcomes that may improve the quality of life for individuals with autism (e.g., language, cognition, daily living).⁷
- Unfortunately, recent research has demonstrated that at least one of the highly regarded Level 1 screening tools is not functioning with the same high level of validity within community samples as was first established within research samples. Specifically, the Modified Checklist for Autism in Toddlers – Revised, with Follow-up interview (M-CHAT-R/F) demonstrated poorer sensitivity (i.e., 33.1-38.8) and positive predictive value (14.6-17.8) within community samples across three large health systems within the United States^{1,2,3,4} than in many research samples (i.e., Sensitivity: 83% PPV: 58%).⁸
- It is possible that at least some of the variability in validity statistics observed between research and community samples may have been driven by administration error (i.e., fidelity of follow-up interview administration¹ and follow-up care/disruptions to follow-up care (i.e., referring for diagnostic evaluation following positive screen, attending diagnostic evaluation visit, long wait lists).⁹ However, there is at least some evidence that a number of M-CHAT-R items in were answered differently across groups in community samples – that was not observed in research samples.¹⁰

Methods

Protocol

The protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA-ScR). Our main objective was to: “Determine the scope to which level 1 autism behavioral screening measures have been created, or adapted, for diverse populations within the United States.”

Eligibility Criteria

To be included in the review, identified manuscripts needed to be original research studies, conducted in the United States, that focused on adapting or creating level 1 screening tools to detect individuals who may have ASD within diverse populations. Table 1 provides detailed definitions of each inclusion criterion.

Information Sources and Search

Our partnering institutional librarians at Henry Ford Health Sladen Library developed and executed the search strategy on the following databases: Ovid MEDLINE, Embase, PsycInfo, and Web of Science. Our partnering librarians conducted our initial search on 6/14/2021, our secondary search on 4/14/2023, and our third search on 11/22/2024.

TERM	DEFINITION
Original Research	We defined original research as studies with human subjects and institutional review board approval.
United States	Research population must be within the United States. For the purpose of this study, we have included studies analyzing patient groups in the 50 U.S. States and Puerto Rico
Autism/ASD	We defined autism spectrum disorder (ASD; autism) as manuscripts that had substantial analytic focus on ASD (i.e., at minimum a sub-analysis focused only on ASD)
Level 1 Screening Tool	We defined level 1 screening tool as any measure that was designed to screen for child behaviors based on parent report as an initial method of screening
Adaptation or Creation of Screener for Diverse Population	We defined <i>adaptation</i> as any measure that was altered (e.g., remove items, add items, translate items). We defined <i>creation</i> as the development of a new measure. We defined <i>diverse population</i> as racial, ethnic, and socioeconomic diversity.

Table 1. Terms and Definitions of Inclusion Criteria

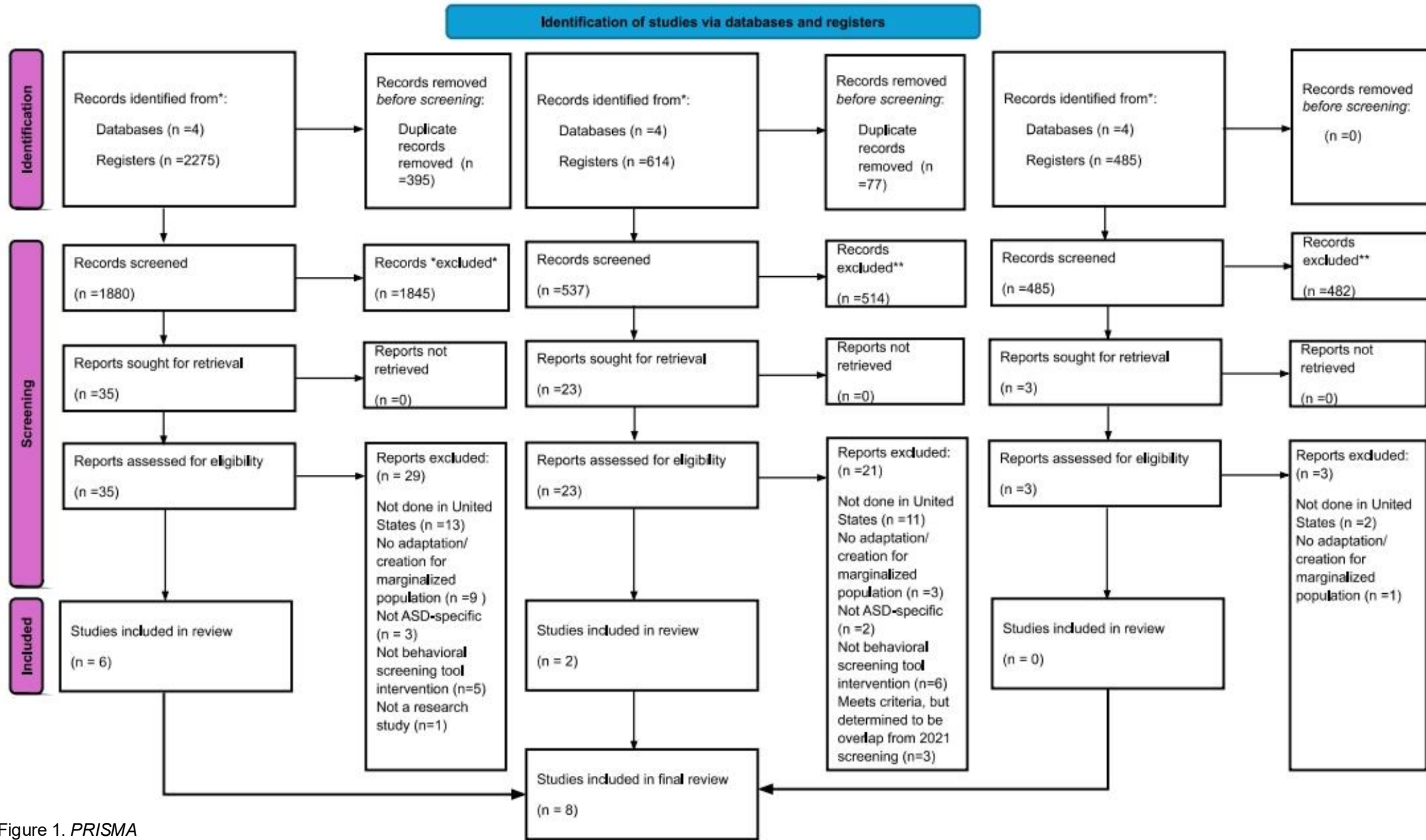


Figure 1. PRISMA

Results

A total of 8 manuscripts were identified by our search that included at least some element of adaptation or creation of Level 1 screening tools for autism withing diverse populations in the United States. Of these manuscripts, 6 featured at least some type of adaptation of existing Level 1 ASD screening tools (M-CHAT-R [3]; First Years Inventory [2]; CARS [1]).

Citation	Screening Tool	Adaptation or Creation	For who?
Kimple KS, Bartelt EA, Wysocki KL, Steiner MJ. Performance of the Modified Checklist for Autism in Toddlers in Spanish-speaking patients. Clinical pediatrics. 2014;53(7):632-8.	M-CHAT-R	Adaptation (comparison of Spanish and Western Hemisphere translations to English version)	Parents of toddlers with origins from Mexico and Central America
McClure C, Reines S, Suchdev PS, Oladele A, Goodman AB. Adapting an Autism Screening Tool for Use in the DeKalb County Refugee Pediatric Clinic. Journal of immigrant and minority health. 2018;20(2):360-9.	M-CHAT-R/F	Adaptation (translation and cultural adaptation)	Parents of toddlers with origins from Nepal
DuBay, M., Watson, L. R., Méndez, L. I., & Rojevic, C. (2021). Psychometric comparison of the English and Spanish western-hemisphere versions of the Modified Checklist for Autism in Toddlers—Revised. Journal of Developmental & Behavioral Pediatrics. 42(9), 717-725.	M-CHAT-R	Adaptation (comparing English and Spanish-Western Hemisphere translations)	Parents of toddlers who speak Spanish
Linares-Orama, N., Miranda, K., & Romero, A. (2019). Identifying robust autism indicators for Latino children. Puerto Rico Health Sciences Journal, 38(2).	CARS	Adaptation	Patients of toddlers living in Puerto Rico
DuBay M, Watson LR, Baranek GT, Lee H, Rojevic C, Brinson W, et al. Rigorous Translation and Cultural Adaptation of an Autism Screening Tool: First Years Inventory as a Case Study. Journal of autism and developmental disorders. 2021.	First Year Inventory – Spanish	Adaptation (translation and cultural adaptation)	Parents of toddlers who speak Spanish
DuBay, M., Sideris, J., & Rouch, E. (2022). Is traditional back translation enough? Comparison of translation methodology for an ASD screening tool. Autism Research, 15(10), 1868-1882.	First Year Inventory – Spanish	Translation (forward-back, with cultural adaptation)	Parents of toddlers who speak Spanish
Janvier YM, Coffield CN, Harris JF, Mandell DS, Cidav Z. The Developmental Check-In: Development and initial testing of an autism screening tool targeting young children from underserved communities. Autism: the international journal of research and practice. 2019;23(3):689-98.	Developmental Check-In (DCI)	Creation (development and initial testing)	Parents of toddlers who a significant proportion speak Spanish, are from a primarily low-income area, and are primarily non-white
Harris JF, Coffield CN, Janvier YM, Mandell D, Cidav Z. Validation of the Developmental Check-In Tool for Low-Literacy Autism Screening. Pediatrics. 2021;147(1).	Developmental Check-In (DCI)	Creation (validation)	Parents of toddlers who a significant proportion speak Spanish, are from a primarily low-income area, and are primarily non-white

Table 2. Summary of level 1 screening tools adapted or created for diverse populations in the United States

Discussion

Adaptation

Five of the 6 adaptation focused research studies focused on aspects of translation. Specifically, studies examined:

- rates of diagnosis between versions,¹³
- psychometric property assessment either between new versions of screening tools or of newly translated screening tools (i.e., M-CHAT-R, FYIv3.1)^{14,15} or
- direct translation and adaptation of existing screening tools (i.e., M-CHAT-R to Nepali; FYIv3.1 to Spanish).^{16,17}

The sixth adaptation focused research study aimed to identify specific items on a screening tool that were most appropriate for identifying autism within a specific population (i.e., CARS, Latino population; Puerto Rico).¹⁸

Creation

Only 2 research studies were identified that focused on the creation of a new screening tool for a specific population within the United States and both research studies focused on the development of the same screening tool, the Developmental Check In (DCI).^{4,19} The first study emphasized development and initial validation.⁴ Whereas the second study was a validation study of the DCI within a general population.¹⁹

The results presented within this scoping review demonstrate that screening tools are being adapted and created for diverse populations within the United States.

However, as anticipated, there is a significant paucity of both the number of adaptations and creations of screening tools for diverse populations within the United States. This varies starkly from the global autism screening adaptation and creation work completed to date.²⁰ Globally, there have been many adaptations and creations for various countries, and cultures within countries. However, in the US, a country with immense diversity, comparatively little work has been done to ensure screening tools for autism that meet these needs.

This scoping review was initiated with the intent of gauging the current levels of accessibility in ASD screening tools and was completed with the hope of better understanding the steps required to achieve equity in this tool that has the potential for a significant impact on the outcome of the lives of millions of children in this country.

Conclusion

There is a paucity of level 1 ASD screening tools adapted or developed with/for marginalized populations in the USA. More US focused adaptation and creation research is necessary to address known limitations of current level 1 screening tools for autism for the diverse population within the USA.

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