A systematic review of research involving ASD screening tools: A roadmap for modelling progress from basic research to population impact

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Presented at the International Society for Autism Research Montreal, QC, CANADA May 2019

Background & Objectives

Concerns about ASD's prevalence and delays in diagnosis mobilized \$2.5 billion in research funding in the United States between 2008 and 2015. Yet recent reports indicate persistent and significant gaps in timely and accurate identification.

We recently reviewed all projects funded through the National Institutes of Health from 2008 to 2013 focused on ASD identification. Only 9 projects (1% of all NIH ASD research funding) focused on improving ASD identification among community providers¹. Do these gaps in research funding in the United States reflect broader gaps in translating research into community practice?

Our objective was to propose a research roadmap for achieving large scale improvements in ASD identification (see Figure 1), in this case focusing on applied research on the Checklist for Autism in Toddlers and its variants (CHAT+). We sought to evaluate the roadmap's utility in capturing publication gaps and trends over time.

Insert Figure 1 about here

Methods

See Figure 1 for categories, stages, subtypes, and milestones of research, and other elements of an integrated network.

<u>Steps</u>

- 1. We conducted electronic database searches for all peer-reviewed publications describing original research involving the development, validation, or implementation of the CHAT+
- 2. We reviewed abstracts to eliminate articles that were not relevant. We conducted full-text reviews to assign studies to subtypes based on primary objectives, and to exclude studies that did not lead to diagnostic evaluations. Additional reviews are underway to capture other study details.
- 3. We have begun to search the internet for the resumes of the first and last authors on all original research studies included in the Roadmap. We have begun to code resumes for evidence of clinical training, and experience delivering services or leading programs. Other details regarding methods are available on our website. As analyses are ongoing,

updates will be posted at regular intervals at <u>http://www.asdroadmap.org/research-roadmap-for-asd-screening.html</u>.

Results and Conclusions

An initial review of almost 200 abstracts yielded 91 relevant research studies involving the CHAT and its variants. Most (74) have involved the M-CHAT. Based on the primary objective, 76 (84%) have been classified as clinical research studies (see Figure 2). Fifteen (16%) focused on implementation or other applied research, often assessing rather than seeking to overcome potential barriers. The lack of implementation research helps to explain persistent gaps in timely and accurate identification, and suggests a need to shift research priorities.

Insert Figure 2 about here

Other emerging findings suggest other areas of growth and reasons for the gaps observed. For example, few studies appear to explore the tool's utility outside of medical settings. An ongoing review of the background and training of first and last authors suggests that few have extensive experience working in more typical, community-based settings.

This review demonstrates the utility of the research roadmap in charting progress. Trends over time in publications of clinical and implementation research involving the M-CHAT (Figure 1) are consistent with the roadmap, with more studies emerging in later years to focus on elements of implementation.

References

1. Doehring, P. (2018, May). Priorities established by the Combating Autism Act for improving ASD identification: Looking beyond ideas and instruments towards implementation. Paper presented at the International Society for Autism Research, Rotterdam, NL.

The author has no conflicts of interest arising from these projects **Peter@asdroadmap.org**

Figure 1: A Research Roadmap for Screening using the CHAT+

PRACTICE	Screening	for ASD
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BASIC RESEARCH

APPLIED RESEARCH

Stage 1: Clinical Research

Aims 1. Pilot the CHAT+. (2) Demonstrate its validity and reliability in a core population. (3) Adapt it for use in community settings. Other steps include extending its use in other populations.

Milestone The CHAT+ is valid and reliable, with the potential to be used effectively by community-based practitioners to accurately screen for ASD within a core population.

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Stage 2: Implementation Research in Community Settings

Aims 1. Assess delivery & gaps in access to the CHAT+ in the community. (2) Demonstrate how to improve delivery & close gaps. (3) Demonstrate systematic & comprehensive regional delivery.

Milestone Community-based programs can be trained to effectively use the CHAT+ to systematically screen for ASD across an entire region, and across diverse populations.



Stage 3: Other Applied Research

Aims. Evaluate how the CHAT+ has been integrated into programs of care, and whether its use has improved overall rates of identification and timely access to specialized intervention. **Milestone** Community-based professionals using the CHAT+ have increased the timely and accurate identification of ASD across the population, integrating screening with other practices.

Type of Research	00	 06	07	08	09	10	11	12	13	14	15	16	17	18
Clinical														
1. Pilot	1									1				
2. Validity/ Reliability		1	1	4			1	2	4	3	1		2	8
3. Adapt for community									2	1		2	1	
Other Cultures				1			2	1		2	3	6	1	2
Other Populations						1				2	2	3	1	
Implementa	tion											_		
 Assess deli access 	ivery									2	2	1		
2. Improve delivery & acc	cess							1					1	
3. Demonstrat regional deliv													1	

Figure 2: M-CHAT Research from 2000 to 2018