Achieving population-level improvements in ASD identification

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ASD Roadmap

Where federally-funded research activities fall short

Background Almost 20 years ago, the CDCs Autism and Developmental Disorders Monitoring (ADDM) Network began estimating ASD's prevalence. Concerns about delays in identification have increased with each report and mobilized advocates to request more research funding. Created in response, the Combating Autism Act (CAA) spurred the allocation of more than $2.5 billion in research and related funding between 2008 and 2015

- Yet ADDM's most recent report indicated that 1/2 of the children identified with ASD by ADDM reviewers had not received developmental evaluations by 3 years of age, and 30% had yet to receive a formal ASD diagnosis by 8 years of age. What explains these gaps in ASD identification? How much research has focused on improving identification among community-based providers? Do we have a research roadmap to achieving real improvements in identification?
- A detailed review of 173 projects focused on ASD identification and funded through the National Institutes of Health (NIH) from 2008 to 2013 (totaling $167 million) revealed only 9 projects (totaling $10 million) focused on improving identification among community-based providers. Moreover, 1/3 of the Principal Investigators of these projects did not appear to be clinically trained, and none had significant experience outside of specialized settings (Doehring, 2018)

Objectives To extend our 2018 analyses by describing how much research funded from 2008 to 2015 concretely demonstrated strategies to improve ASD identification among community providers, as part of a larger research roadmap.

Methods We developed a Research Roadmap for ASD Identification (Figure 1), and aligned it with goals of the Inter-Agency Autism Coordinating Committee's (IACC) Strategic Plan (Figure 2). We downloaded Question 1 data from the Autism Research Database (ARD) to extend analyses to 2015 and all funders. These preliminary analyses are based on categories assigned in the ARD; individual project reviews will be conducted in a later phase.

Figure 1: A Research Roadmap for ASD Identification

STARTING OBJECTIVE: Define the core features of ASD		BASIC RESEARCH
Causes / *Characteristics* / *Trajectories* / *Sub-types*		
↓		
1ST MILESTONE: List of specific indicators and assessments for identifying ASD		
2nd OBJECTIVE: To develop tools and practices to identify ASD	Clinical Research	APPLIED RESEARCH
Pilot tool → *Validate tool* → *Demonstrate reliability and usefulness of tool*		
↓		
2nd MILESTONE: Valid & reliable tools appropriate for a range of professionals		
3rd OBJECTIVE: Demonstrate how community professionals can identify ASD	Implementation Research	
Assess, then improve		
Delivery / *Access* / *System capacity*		
↓		
3rd MILESTONE: Community-based professionals can use valid & reliable tools and practices to identify ASD on a large scale & across diverse populations,		
4th OBJECTIVE: Confirm population-level improvements in identification	Other Research	
Prevalence / *Population outcomes*		
4th MILESTONE: Community-based professionals, using valid & reliable tools & practices, have improved identification of ASD across the entire population		

Figure 2: IACC Goals (Question 1) aligned with Research Roadmap

1. Basic Research: Utility of genetic testing (Q1.S.E); Ethical, legal, and social implications of research (Q1.S.F); Behavioral and biological markers (Q1.L.A); Measures of behavioral and/or biological heterogeneity (Q1.L.B); Continuous dimensions (Q1.L.C)
2. Clinical Research: New diagnostic tools for diverse samples (Q1.S.A), Improved screening and diagnostic tools (Q1.S.B)
3. Implementation Research: Impact of early diagnosis on outcomes (Q1.S.D); Disparities in access to diagnosis (Q1.S.C)

Other Projects (Q1.-Other) Categorization unclear

Results and Conclusions The investment in ASD identification between 2008 and 2015 was significant: 399 research and related projects, from 1 to 8 years in duration (Figure 3). Relative to total funding, this peaked at 13% in 2009, and decreased to 8-9% by 2015 (Figure 5).

- Only 20 projects worth $12 million appeared to be aligned with implementation research goals, or less than 1% of total effort towards identification (Figures 3 & 5). This number may increase somewhat when the 65 projects involving clinical research (worth $47 million) are individually reviewed.
- Public agencies like the Health Resources and Services Administration (HRSA) and Agency for Healthcare Research and Quality (AHRQ) placed greater emphasis on implementation, while other public agencies like NIH and National Science Foundation (NSF) made the biggest investments (Figure 4).
- Ninety (23%) of Q. 1 projects were not clearly aligned with any of the IACC's goals, raising questions about whether we have a clear national strategy.
- In general, the persistent gaps in timely and accurate identification of ASD may not be surprising given than only 85 projects (totaling less that $60 million, or only 2% of total funding) were devoted to the clinical and implementation research that could begin to close these gaps in the immediate future.
- Next steps include reviewing:
  - Individual abstracts to identify all possible projects with a focus on clinical or implementation research related to ASD identification
  - Resulting publications from PIs to identify the actual impact in terms of the practical knowledge gained and the number of people who benefited.
  - The background of PIs and co-authors to understand how this might explain the limited investment in implementation research, including: evidence of clinical training; meaningful experience in delivering education, treatment, and training in community settings; an ongoing role in shaping specific policy initiatives relative to services, and; experience leading specific, community-based programs of services and training.

Figure 3: Public, private, and total research funding, 2008 to 2015

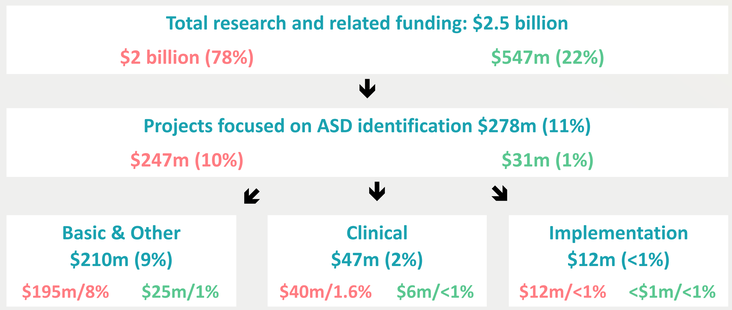
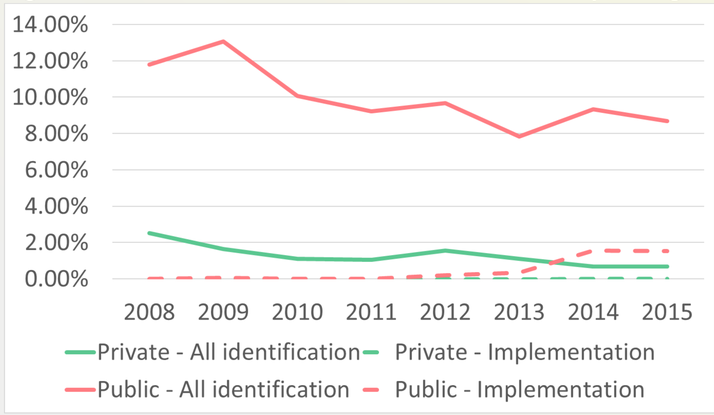


Figure 4: Top three funders of projects involving implementation

Relative to their overall funding	Overall amount
AHRQ: 2.2% ($99,999)	NIH: $9.6m
HRSA: 1.7% ($1,200,000)	HRSA: $1.2m
Organization for Autism Research: 1.3% ($30,000)	NSF: $0.5m

Figure 5: Research Priorities as a function of overall spending



References

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