

Is there evidence that ASD research has impacted policy and outcomes on a national scale?

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ASD Roadmap
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OCALICON 2018

The gap
ASD research ⇔ outcomes?

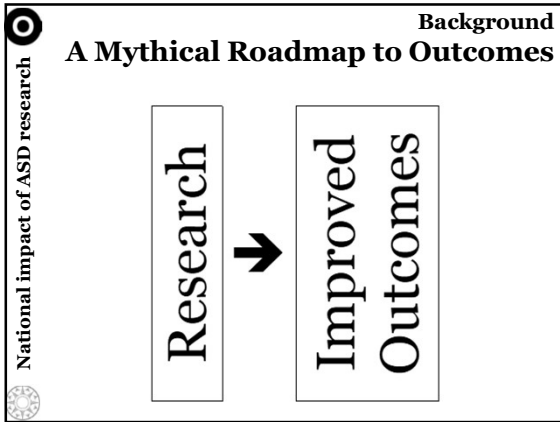
National impact of ASD research

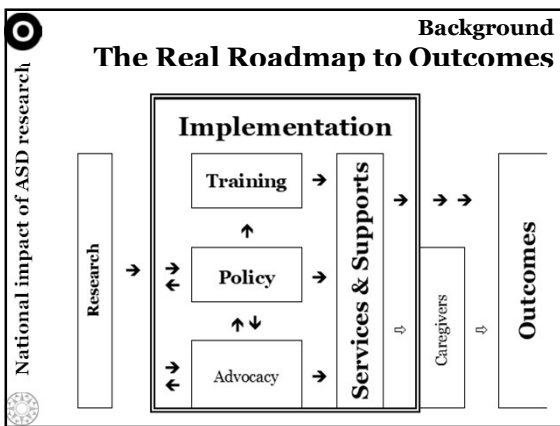
- ❖ ASD research has exploded over the past two decades
 - We invested \$2.5 billion in research and related projects between 2008 and 2015
 - Outcome research has begun to demonstrate benefits of effective intervention
- ❖ But national surveys demonstrate gaps between what we know is possible, and what people can typically achieve
 - ADDM: Persistent gaps in timely and accurate diagnosis
 - National ASD Indicators Reports: Most adults are isolated and un/under-employed

Today's talk

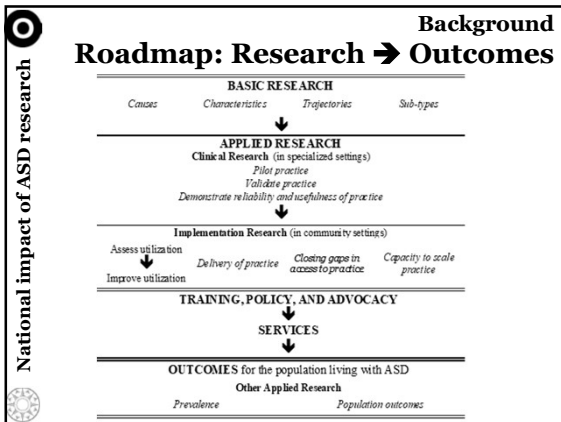
National impact of ASD research

- ❖ Has research measurably influenced policy or outcomes on a national scale?
 - Shifts focus on to specific kinds of research that might influence specific kinds of policy
- ❖ Three different, major initiatives offer lessons about these complex relationships
 - Vaccination
 - ASD identification
 - Autism insurance mandates



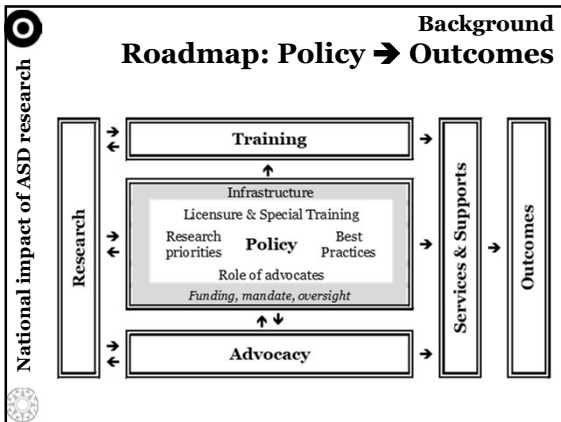


- Background**
The different types of research
- ❖ Basic Research
 - ❖ Applied research
 - Clinical research
 - Implementation research
 - Other research?
 - ❖ Each kind of research
 - Emphasizes different kinds of designs
 - Demands different kinds of expertise
 - Depends on different kinds of partnerships
- National impact of ASD research



- Background**
The different forms of policy
- ❖ Focusing on specific policy decisions
 - ❖ Many different kinds of policies can affect decisions about which services are used
 - Laws / regulations directing practice versus guidelines encouraging practice
 - Policies can be set at the national, state and local/agency level
 - Policies guiding broader groups (those with disabilities) often have a greater impact on services than ASD-specific policies

- Background**
The different targets of policy
- ❖ Training: Licensure and supplemental training
 - ❖ Services: Best practice guidelines
 - ❖ Research: Priorities
 - ❖ Advocates: Role in decision making
 - ❖ Infrastructure
 - Funding levels
 - Mandate
 - Support and oversight



Case study: Vaccinations
Vaccination policy

- ❖ Policy on nature and timing of vaccinations at multiple levels
 - National Guidelines by government and professional bodies
 - State policies for funding and exemptions
 - National Vaccine Injury Compensation Program (“Vaccine Court”)
 - CAA: Cutting of funding for vaccine-related research

Case study: Vaccinations
Vaccination research

- ❖ A variety of research studies on vaccines have contributed to the policy
 - Wakefield’s original study, now withdrawn, continues to inspire conspiracy theories
 - Subsequent related treatments (chelation, specialized diets) involving basic research sparked interest but yielded few if any results
 - Surveillance revealed no clear correlation between changes in policies and prevalence
 - Lesson: Response of science to ill-informed advocacy

Case study: CAA
CAA and ASD diagnosis

National impact of ASD research

- ❖ Reports of increased prevalence has galvanized the ASD community
 - 1990’s: 1 in 2500 → 2018: 1 in 58
- ❖ As result, the Combating Autism Act (CAA) was passed in 2008
 - 2008-2015: \$2.5 billion in public and private funding for research and related projects

Case study: CAA
CAA and ASD diagnosis

National impact of ASD research

- ❖ CDC’s latest report: Many children with ASD appear to be missed
 - 1/2 had not received developmental evaluations by 3 years of age
 - 30% had yet to receive a formal ASD diagnosis by 8 years of age.
 - Wide variations across states and groups
- ❖ These gaps raise important questions about research, policy and outcomes
 - Who is missed and why?
 - Has CAA research focused on improving diagnosis among community-based providers?

Case study: CAA
Who is missed and why?

National impact of ASD research

OCALI 2017: For every 100 children with ASD in SC

Related difficulties missed: 50	Seen by a specialist: 50	
	ASD Signs noted: 6	ASD diagnosed: 42
	ASD signs missed: 2	Missed by school: 19

Case study: CAA
A national research strategy?

National impact of ASD research

- ❖ Key players and elements:
 - IACC: Inter Agency Autism Coordinating Committee based in NIH
 - OARC: Office of Autism Research Coordination
- ❖ IACC creates a national strategy for research priorities and goals
 - IACC has directly allocated funding very rarely
- ❖ OARC reports on public / private research allocations according to IACC goals
 - ARD: Autism Research Database

Case study: CAA
A national research strategy?

National impact of ASD research

- ❖ Of the \$2.5 billion spent on research and related projects from 2008 to 2015 , OARC could align 75% with specific IACC goals?
 - BUT OARC could not clearly align \$637 million, or 25% of the total budget
 - Worse among public funders: 28% of total funding could not be aligned, and this has not improved since 2009

Case Study: CAA
Screening: A Research Roadmap

National impact of ASD research

STARTING OBJECTIVE: Define the core features of ASD
Causes Characteristics Trajectories Sub-types

1st MILESTONE: Specific indicators and assessments for identifying those at high risk for ASD

2nd OBJECTIVE: Develop a tool that can be used to assess the risk for ASD
Pilot tool
Validate tool
Demonstrate reliability and usefulness of tool

2nd MILESTONE: Valid, reliable screening tool appropriate to various professionals & settings

3rd OBJECTIVE: Demonstrate how community professionals can screen for ASD
Assess Delivery of Access to screening Capacity to scale
Improve screening screening screening

3rd MILESTONE: Community-based professionals use valid, reliable screening tool, across large and diverse populations, to refer young children at risk for ASD for diagnostic assessment

4th OBJECTIVE: Document how better screening has improved identification across the board
Prevalence Population outcomes

4th MILESTONE: Community-based professionals using valid, reliable screening tools have increased the timely and accurate identification of ASD across the entire population

BASIC RESEARCH
 Clinical Research
 APPLIED RESEARCH
 Implementation Research
 Outcome Research

Case study: CAA
A focus on implementation?

- ❖ What was spent on demonstrating how to improve diagnosis in community?
- ❖ 1. Based on codes assigned by OARC?
 - 1% of total funds, or 5% of all funds dedicated to improving ASD identification, from 08-15

Total research and related funding: \$2.5 billion		
↓		
Projects focused on ASD identification \$278m (11%)		
↙	↓	↘
Basic & Other \$210m (9%)	Clinical \$47m (2%)	Implementation \$12m (<1%)

Case study: CAA
A focus on implementation?

- ❖ 2. Based on reviews of principle aims within each project in relevant categories?*
- Of the 173 NIH-funded projects from 2008-13 (\$167m) focused on identification....
 - 9 projects worth \$10m (or 6% of overall funding) demonstrated community implementation
 - Why the gap? 1/3 of PIs were not clinically trained, and none had meaningful community experience
- ❖ Other efforts: Expansion of LENDS, ATNs, and state initiatives around Learn the Signs Act Early

* 2018, International Society for Autism Research, Rotterdam

Case study: Insurance
State ASD Insurance mandates

- ❖ Originally inspired by findings from EIBI
- ❖ Reframed by Autism Speaks as a major state policy initiative
 - Now passed in 46 states
- ❖ Mandell et al (2016) looked at data from 29 state between 2008 and 2012
 - Insurance mandate eventually appeared to increase treated prevalence by 18%
 - BUT treated prevalence of 1.8/1000 is less than 1/8th of overall estimated prevalence

Conclusion
A remarkable gap!

National impact of ASD research

- ❖ Few examples of specific research studies that shaped specific national policy decisions to result in large-scale impact
- ❖ This says a lot about
 - The complexities of policy and its relation to services and outcomes
 - The limits of the predominant models of / approaches to research
 - The need for true collaboration between researchers and policymakers, especially in the promotion of implementation research

Conclusion
A remarkable gap!

National impact of ASD research

- ❖ If current ASD treatments are not informed by ASD's presumed genetic or neurological causes, what role can basic research play in improving outcomes now?
- ❖ If most treatments are educational or behavioral, and evidence-based practices are not universally used, why not invest in implementation research?
- ❖ A lesson: Teaching Margot to ski
 - None of the techniques depended on understanding the causes of Margot's disabilities

For more information

National impact of ASD research

- ❖ (2019). The Impact of ASD Research on National Policy: Lessons from the Combating Autism Act and the National Institute for Health and Care Excellence. In Volkmar, F. *Autism and Pervasive Developmental Disorders* (3rd ed.). Cambridge University Press.
- ❖ Peter@asdroadmap.org

ASD Roadmaps

