Making prevalence relevant, again

Re-analyzing CDC data to target gaps in ASD identification

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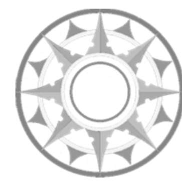
ASD Roadmap
November 7, 2017



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MISCONCEPTIONS ABOUT CDC's PREVALENCE RESEARCH

1. Methods for capturing population prevalence yield data too questionable to use
2. We cannot craft a national strategy without a precise estimate of population prevalence
3. Children whose ASD is missed are not getting any help

- **Can we use existing CDC data to challenge these assumptions and misconceptions?**

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1. ADMINISTRATIVE NOT POPULATION PREVALENCE

- ❖ Administrative prevalence: The number already labeled with ASD in our systems of care
- ❖ CDC samples 8 year-old children referred to specialists and centers
- ❖ So what is the CDC's measuring?
  - – Not population prevalence
  - – Optimal administrative prevalence, or the number of children with ASD amongst those already referred to systems of care

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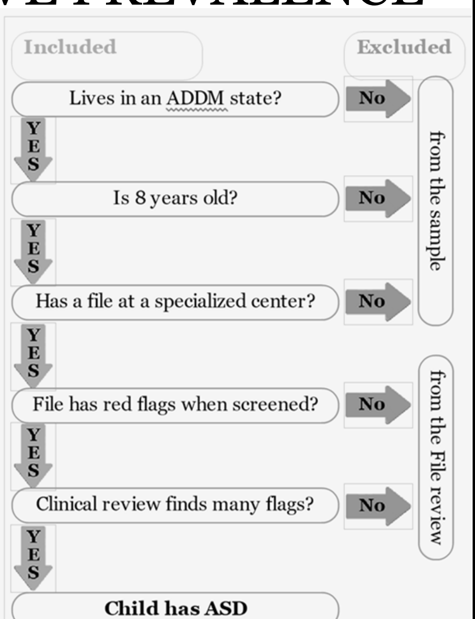
ADMINISTRATIVE PREVALENCE

CDC's Methods

- ❖ Provides a valid estimate for those
  - – Already identified with ASD
  - – Who would be diagnosed if properly assessed
  - – Estimates based on file review are comparable to those based on full clinical assessment



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2. USE DISPARITIES IN ADMINISTRATIVE PREVALENCE

- ❖ A single, precise, and reliable, national estimate of administrative prevalence
  - May be <u>unrealistic</u> because of regional variations in services
  - Is <u>unnecessary</u> if we focus on disparities within & across states with available data
- ❖ Disparities across states may capture state—state differences in practices & systems of care
- ❖ Disparities within states may capture
  - Local differences in practices & systems of care
  - Disparities due to race, ethnicity, income

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DISPARITIES IN PREVALENCE

Closing Pennsylvania's Gaps

- ❖ In 2011, rates of identification per 10,000 varied from 11% to 39% of CDC's projections of 1 in 68
  - For every child identified in a Pennsylvania County in 2011, 2 to 8 more might be missed
  - Maybe 50% will be identified by 2023… or 2061
  - Prevalence falls short despite Autism insurance, State Autism Agency, strong research centers
- ❖ Who cares if prevalence is 1 in 58 or 68 or 78 when so many diagnoses are missed
- ❖ CDC's data reveal gaps that tell us a lot about
  - How many we are missing
  - Who are we missing?
  - How we are missing them?

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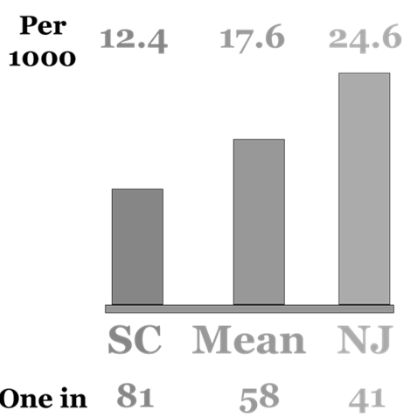
HOW MANY ARE WE MISSING

Estimating complete misses in SC

- Complete miss: A child never diagnosed with ASD, maybe never seen by a specialist
- Contrast prevalence in highest (NJ) and lowest (SC) states
  - For every child CDC identified with ASD in SC, another was completely missed



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HOW ARE WE MISSING THEM

Children who maybe got help in SC

ASD caught: 42%

Targeted via school services: 22%

Diagnosed by hospital but missed by school: 13%

ASD missed, other help sought: 13%

Caught ASD signs: 8%

Missed ASD signs: 5%

All difficulties completely missed: 45%

- Projections derived from merging NJ and SC prevalence data with 2011 validity study

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WHO ARE WE MISSING
Ethnic Disparities for SC

- For every 10 Hispanic children CDC identified with ASD in SC,
  - Another 10 to 20 might be completely missed
  - Only 1 or 2 might have a special education record that identifies ASD as their primary educational classification

ASD Roadmaps

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Using data from the ADDM network to help close gaps in implementation

Questions we can ask

Some background

Estimates of ASD's prevalence reveal that many children may not be properly identified with ASD, let alone benefit from specialized services. This widening gap should concern advocates, researchers, policy makers, and program leaders alike.

How do you estimate the prevalence of ASD?

Estimating how many people have a rare and complex condition is a difficult task. The CDC's approach to select and evaluate a sample of children has raised important questions. Do these yield estimates that are reliable enough to begin to build on?

What we may learn

Missing ASD has great consequences. Developing programs to catch it takes time, but must be prioritized

These data can help generate hypotheses about trends in identification without knowing ASD's true prevalence

For more information

www.asdroadmap.org/making-prevalence-relevant-again.htm

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