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Re-analyzing CDC data to target gaps in ASD identification

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ASD Roadmap

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## BACKGROUND

- Population prevalence: How many people have an identified condition across the entire population in the country, regardless of whether they have been identified yet
  - Increases in prevalence grab the attention of the public and policymakers
- The consequences of being missed
  - Child does not access specialized programs
  - Work in creating effective programs is wasted

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## MISCONCEPTIONS ABOUT CDC's PREVALENCE RESEARCH

1. We need to know ASD's population prevalence to plan our treatments and services
2. CDC's methods yield data too questionable to use
3. We cannot craft a national strategy without a precise estimate of population prevalence
4. Children whose ASD is missed are not getting any help
5. Timely and accurate diagnosis
   - Guarantees better treatments and outcomes
   - Is ensured with better screening

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

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# ADMINISTRATIVE PREVALENCE
## What is it?

- ❖ Administrative prevalence: How many people have an identified condition only among those who have already begun to receive help as a result of a diagnosis
  - Can be identified by schools, hospitals, community services….
- ❖ Not viewed by researchers as "True prevalence", because it varies as a function of the systems in place

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# ADMINISTRATIVE PREVALENCE
## Closing Pennsylvania's Gaps

- ❖ In 2005, rates of identification per 10,000 varied from 6% to 21% of the CDC's projections

and Total Number (in parentheses) with Diagnosis of ASD
Being Served by DPW and/or PDE in 2005
State: 15.98 (19,862 - includes persons whose county of residence is unknown)

Warren 32.12

CDC rate 147

Adams 8.92

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# ADMINISTRATIVE PREVALENCE
## Closing Pennsylvania's Gaps

Prevalence Rate of Individuals with Autism Receiving Services in Pennsylvania, per 10,000 County Residents in 2011
(Total Number of Individuals with Autism Receiving Services in Parentheses)

Clearfield 57.1

CDC rate 147

Sullivan 15.6

- ❖ In 2011, rates of identification per 10,000 varied from 11% to 39% of CDC's projections of 1 in 68

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## ADMINISTRATIVE PREVALENCE
**Closing Pennsylvania's Gaps**

- Who cares if "true" prevalence is 1 in 58 or 68 or 78 when so many diagnoses are missed
  - 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

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## REPURPOSE PREVALENCE DATA

- Are the CDC's data strong enough to merit a more detailed analysis based on disparities in administrative prevalence?
- If so, can they reveal
  - How many children we might be missing in each state?
  - The characteristics of children we are most likely to miss?
  - The stage in the process where they are most likely to be missed?
  - The impact of being missed?

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## REPURPOSE PREVALENCE DATA
**The ADDM network**

Autism and Developmental Disabilities Monitoring (ADDM) Network Sites

Tracking Year 2012 Sites

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## REPURPOSE PREVALENCE DATA
### ADDM Methods

- Who is included in a CDC prevalence study?

Included | Excluded

Lives in an ADDM state? → No
YES
Is 8 years old? → No
YES
Has a file at a specialized center? → No
(from the sample)
YES
File has red flags when screened? → No
YES
Clinical review finds many flags? → No
(from the File review)
YES
Child has ASD

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## REPURPOSE PREVALENCE DATA
### Limitations of ADDM's estimates

- Not based on direct assessments, but on a review of clinical file, and so depend entirely on quality of professional's notes
- May miss some with milder symptoms, in poverty, & from racial/ ethnic minorities
- Will miss those never evaluated or treated in a specialized health/education program
- Reflect diagnostic practices from 8 years earlier

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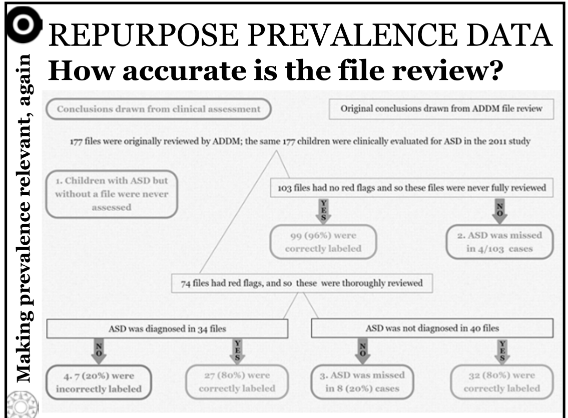
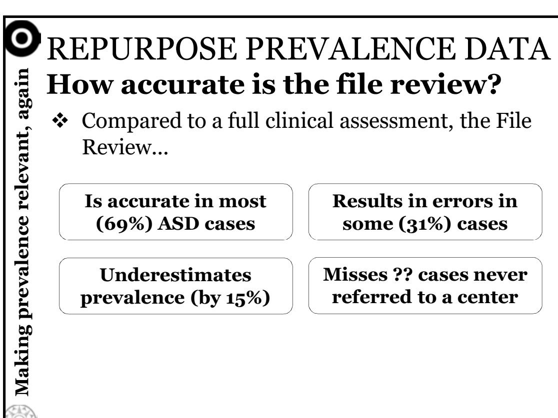
## REPURPOSE PREVALENCE DATA
### How accurate is the file review?

- Children with ASD with no file were never screened, and so were completely missed
- Of those later clinically diagnosed w/ ASD
  - Red flags completely missed in 10% of cases
  - Signs of ASD were detected, but diagnosis was missed in 20% of cases
- 15% were incorrectly diagnosed with ASD based on the file review

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## REPURPOSE PREVALENCE DATA

### How accurate is the file review?

- ❖ The File Review is adequate for identifying broad disparities within and across states
  - Same methods used in different states
  - Shared fidelity standard across state teams
- ❖ Rates of misdiagnosis are not optimal, but does not preclude some comparisons
  - Are certain children more likely mislabeled?

## REPURPOSE PREVALENCE DATA
**How accurate is the file review?**

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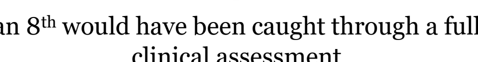
- The File Review may under-estimate "true" population prevalence

For every 7 children identified with ASD through a file review



an 8th would have been caught through a full clinical assessment

## USE PREVALENCE DISPARITIES
**Why?**

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- A single, precise, and reliable, national estimate of administrative prevalence
  - May be unrealistic because of regional variations in services
  - Is unnecessary 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

## USE PREVALENCE DISPARITIES
**When ASD is completely missed**

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- All difficulties missed? Child never referred to a specialist for any help
  - Signals a more significant breakdown in early intervention and special education
- ASD missed? Child was referred to a specialist for other difficulties but ASD was not identified

Included | Excluded
Lives in an ADDM state? — YES / No
Is 8 years old? — YES / No (from the sample)
Has a file at a specialized center? — YES / No
File has red flags when screened? — YES / No
Clinical review finds many flags? — YES / No (from the File review)
Child has ASD

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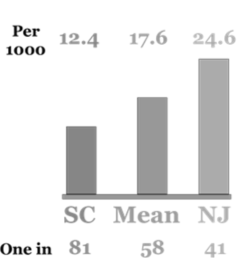
# USE PREVALENCE DISPARITIES
## Estimating complete misses

- Calculated by contrasting prevalence in highest state (NJ) with other states in ADDM
  - Lowest prevalence in using health and school data: SC

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# USE PREVALENCE DISPARITIES
## Estimating complete misses in SC

For every 10 children identified with ASD in SC using a file review

XXXXXXXX

ASD was missed in 10 more children

With all other difficulties missed in most cases

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# USE PREVALENCE DISPARITIES
## Disparities related to race/ethnicity

- Previous research: Hispanic and African American children are under-diagnosed, mis-diagnosed, or diagnosed late
- ADDM network found similar disparities
  - 12 white children were identified for every 10 black children
  - 15 white children were identified for every 10 Hispanic children
- Disparities are magnified by state to state variations and how children are missed

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# USE PREVALENCE DISPARITIES

**Ethnic Disparities in SC**

For every 10 Hispanic children identified with ASD

Another 9 children were completely missed
And 9 more children relative to prevalence in NJ
With all other difficulties missed in most cases

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# JUST MISSING ASD

- How we almost catch a child's ASD: A child is referred for other help and
  - ASD is caught by one professional but missed by others
  - ASD is caught at one time and missed later
  - Signs of ASD are noted but are misinterpreted

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# JUST MISSING ASD

**ASD caught: 70%**

Diagnosed by hospital but missed by school: 13%

ADDM Prevalence Study, 2016

**ASD missed, other help sought: 30%**

Caught ASD signs: 20%

Missed ASD signs: 10%

ADDM Validation Study, 2011

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# JUST MISSING ASD
## Implications for system change

- ASD is caught by one professional but missed by others? Improve collaboration
- Signs of ASD are noted but are misinterpreted? Train specialists to disentangle ASD from other conditions
- Signs of ASD are completely missed? Train specialists to identify ASD
- ASD screening tools will not be as accurate for children already referred to specialists

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# JUST MISSING ASD
## Likely outcomes in SC

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

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# ROADMAP TO IDENTIFICATION
## The on ramps

- We cannot fix identification without understanding the process by which community providers catch ASD
- Children may be picked up
  - By different providers (school, hospital, EI)
  - At different ages
  - For different reasons (co-occurring behavioral problems or intellectual disability)
  - These differences create different routes

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## ROADMAP TO IDENTIFICATION
### The detours and roadblocks

- Detours and roadblocks vary from route to route
  - A child from a poor family or rural region may lack transportation
  - A parent without a high school education or who does not speak English might be unable to navigate the system
  - A school-aged child might be diagnosed with anxiety, ADD, or conduct problems
  - A black or Hispanic child is assumed to just have a conduct disorder
  - A girl's ASD might simply be unnoticed
  - A gifted child's isolation might just be ascribed to awkwardness

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## LOOK BEYOND IDENTIFICATION
### Beyond professionals to systems

- Stop assuming professionals just need more training!!
- A professional might not
  - Screen an 18-month old because of a 2-24 month wait for a medical diagnosis
  - Diagnose ASD because there are no specialized programs in the school, hospital, or community
  - Refer a child at risk because there is no history of cross-sector collaboration

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## LOOK BEYOND IDENTIFICATION
### ASD Screening is insufficient

- Being diagnosed is no guarantee of specialized service
  - Maybe ASD specialized services are not available
  - Maybe other difficulties are deemed more important
- Missing an ASD diagnosis does not mean a child is not getting help

## 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

*To contact me*
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