HEALTH CARE AND HUMAN SERVICES POLICY, RESEARCH, AND CONSULTING - WITH REAL-WORLD PERSPECTIVE.

Study of Health Outcomes in Children with Autism and Their Families

Presentation for Interagency Autism Coordinating Committee

January 29, 2013

Discussion Outline

- **Project Overview**
- Key Findings
- Questions

Project Overview

Research Team

- The Lewin Group
- OptumInsight
- OptumHealth
- Drexel University

Objective

Use existing administrative data to further our understanding about Autism Spectrum Disorders (ASD), including:

- diagnosis,
- risk factors,
- health outcomes of children with ASD and their family members,
- health care use by children with ASD and their family members.

Deliverables

- 5 reports
- 3 manuscripts
- Dataset delivered to National Database for Autism Research (NDAR)

What are Administrative Claims Data?

- Data submitted by providers (e.g., doctors, hospitals, etc.) to payers (e.g., health insurance companies) for payment of services
- Procedures/services not covered by health plan (e.g., ABA, speech therapy offered at school) are not included
- Usually does not include all of the clinical information related to an individual

Study Sample Information

Data Set Attribute	Description
Timeframe to be used in study	2001-2009
Medical information	Diagnosis code(s), procedure code(s), some provider characteristics (e.g., specialty), cost/payment (health plan and beneficiary responsibility)
Pharmacy information	Drug, dosage, length of script in days, minimal information on prescriber
Mental & behavioral health information	Similar information to medical claims for individuals with behavioral health coverage (ASD covered at least partially)
Sociodemographic (income and race)	Not available in claims data but our data is linked to outside source of data about income and race, but missing in 40-50% of sample.
Family linkage	Logic included in our programming to identify likely parent and siblings with the same insurance
Representation	Dataset is geographically diverse across the US and fairly representative of the population

Study Sample Size

Sample Description	Sample Size (ASD)*	Comparison Group (no ASD)
Children	46,236	138,876
Parents of children	80,164	232,229
Siblings of children	57,056	195,868

*Presence of one or more claims with an ICD-9 for Asperger's, Autism, or PDD-NOS

- Approximately 80% of the children with ASD were male
- Just over half of the sample was between 2-10 years of age
- Race/ethnicity was not available for ~ half of the children, but for those where it was available over 75% were white

A Chart Review informed our identification of children with ASD using claims data

- Using ~430 medical charts, we assessed the extent to which a claim with an ASD diagnosis was confirmed by clinical information in the physician's chart
  - If a child had one claim with an ASD diagnosis, the Positive Predictive Value (PPV)=74.2%
  - If a child had two or more claims with an ASD diagnosis, the PPV increased to 87.4%
  - Thus, the rest of our analysis only included children with 2 or more ASD diagnosis codes in claims as having ASD (n=33,565).

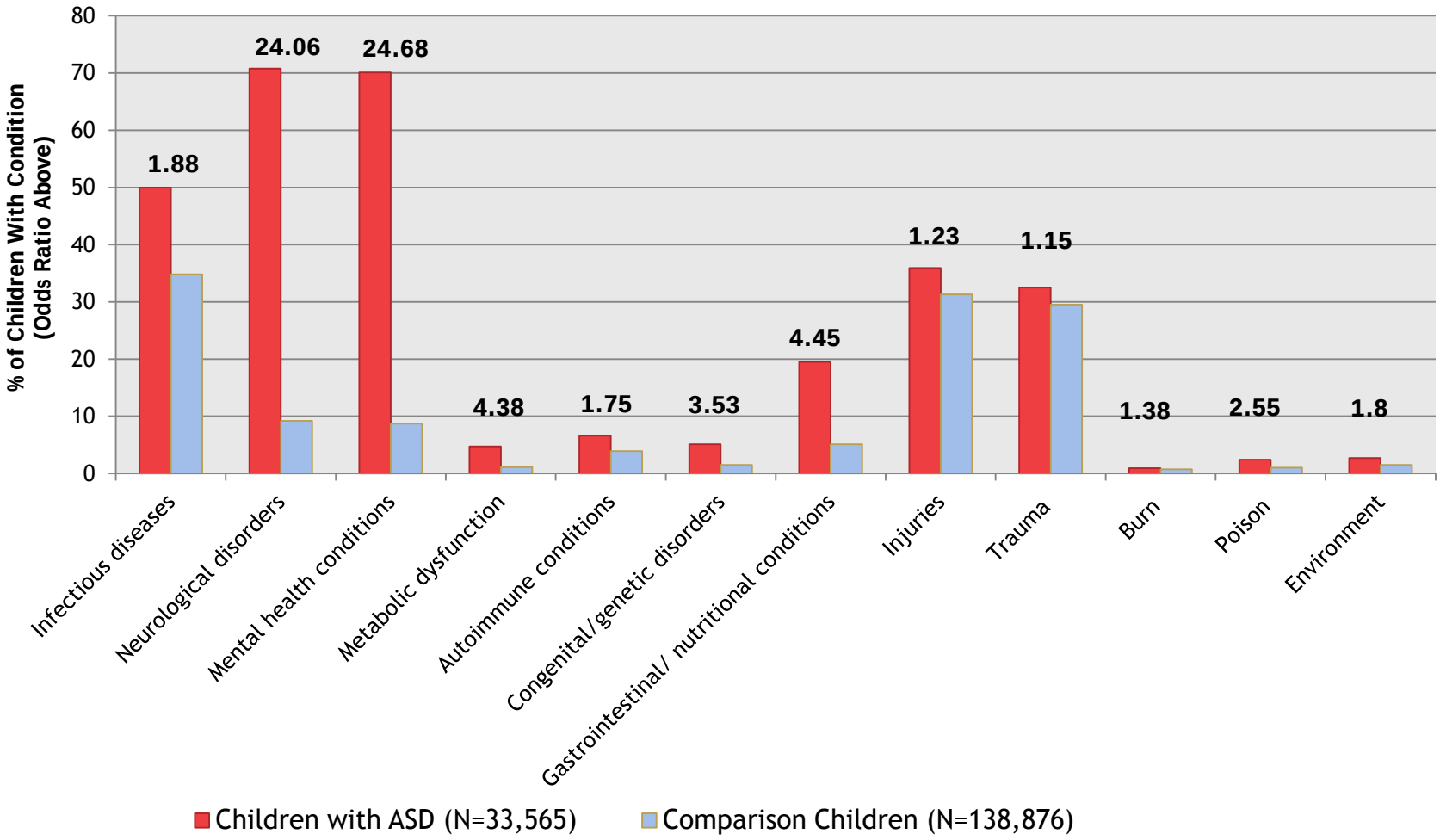
Discussion Outline

Project Overview

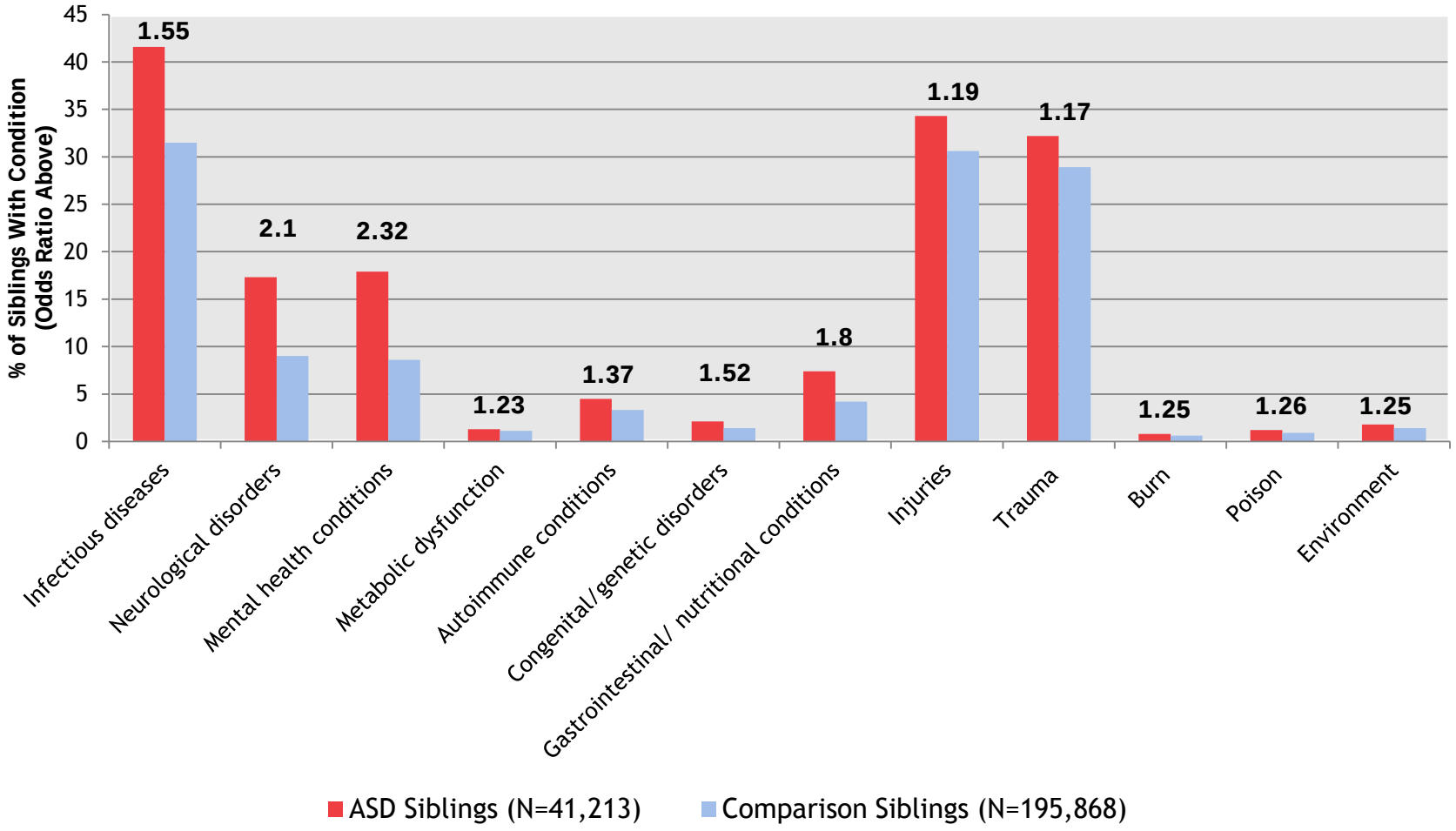
Key Findings

Questions

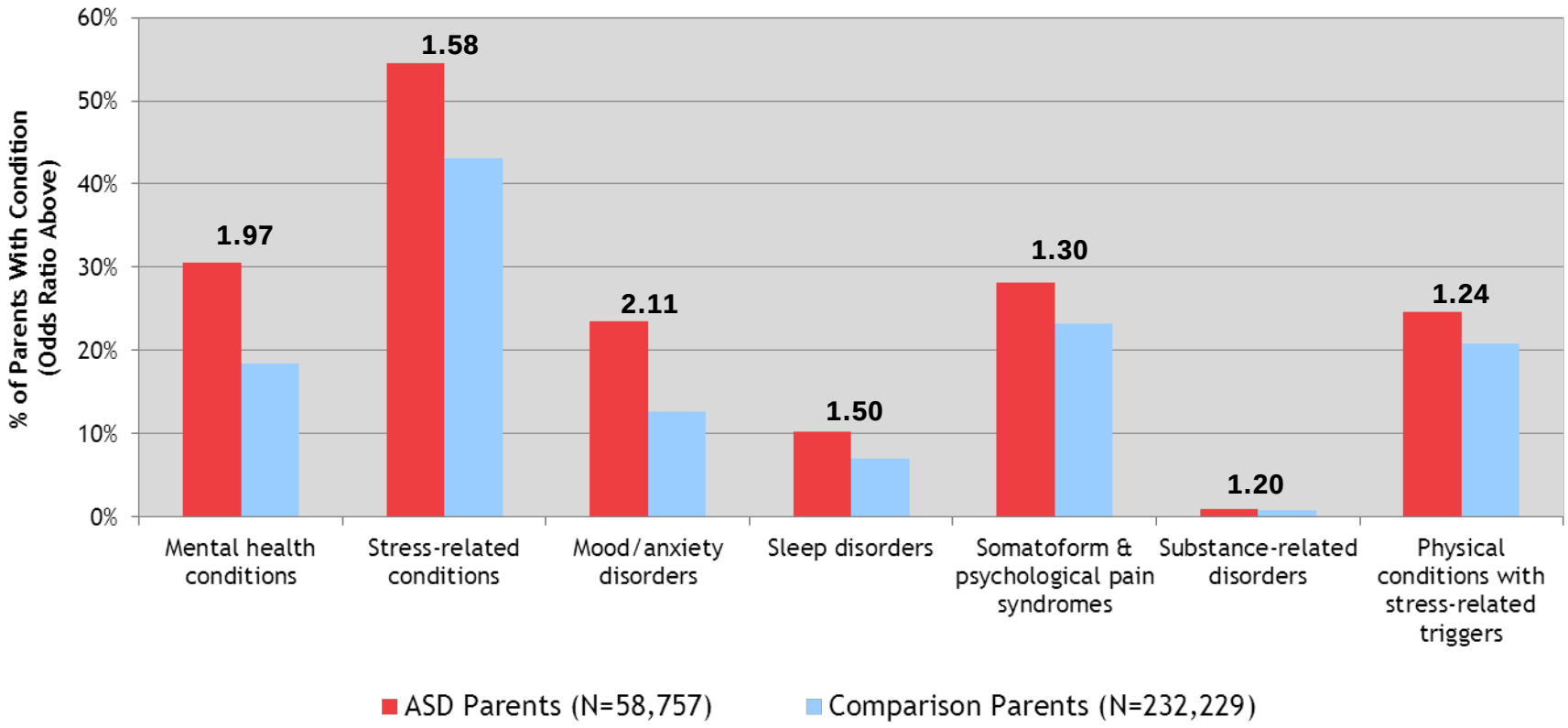
Health Outcomes:
ASD vs. Comparison Children



Health Outcomes:
ASD Siblings vs. Comparison Siblings



Health Outcomes:
ASD Parents vs. Comparison Parents



Gastrointestinal Disorders among children with and without ASD

Research Topics

We studied:

1. The occurrence of gastrointestinal conditions in children with ASD compared to those without, and
2. How the occurrence of GI conditions changed after the ASD diagnosis compared to before the ASD diagnosis.

Results

We found that:

1. Children with ASD were much more likely to have a GI condition than children without ASD (OR = 3.94).
2. The odds for having a GI condition were higher in the 12 month period after the ASD diagnosis than the 12 months before (OR= 1.39).

Parental stress-related conditions

Research Topics

We studied:

1. The occurrence of stress-related conditions in parents of children with ASD compared to parents of children without ASD, and
2. The occurrence of stress-related conditions in parents following his/her child's initial ASD diagnosis compared to before the diagnosis.

Results

We found that:

1. Parents of children with ASD had higher odds of having a stress-related condition than parents of children without ASD (OR=1.48).
2. Among parents of children newly diagnosed with ASD, the odds of having a stress-related condition were higher in the 12 month period after the child's diagnosis (OR=1.32) than in the 12 month period before.

Health Care Use: ASD and Comparison Children

- Children with ASD had an average of 21 total health care visits (office and outpatient) annually, as compared to 5 visits for children without ASD
  - Children with ASD had an average of 11 total behavioral health visits (subset of total health care visits), compared to less than 1 for children without ASD
- Children with ASD were prescribed, on average, ~3 unique medications annually, compared to ~2 unique medications for children without ASD

Adherence to MMR Vaccination

Research Topics

We studied:

1. The relationship between diagnosis of ASD in a child and MMR vaccination rates among younger siblings (12-24 month old group)

Results

We found that:

1. Younger siblings of children with ASD were less likely to be vaccinated with the first MMR than their older siblings with ASD (69.2% vs. 82.2%)
2. Younger siblings of children with ASD were less likely to be vaccinated with MMR than younger siblings of children without ASD (69.2% vs. 84.9%).

Topics Pending Publication

Research Topics

1. Injury Among Children With Autism Spectrum Disorders
2. Psychotropic Medication Use and Polypharmacy in Children with Autism Spectrum Disorders

Results

The results to these research questions are currently under consideration for publication.

Utility of Claims Data for ASD Risk Factor Research

- We assessed whether claims data could be useful in future research to examine risk factors for ASD:
  - Early life risk factors in children
  - Maternal risk factors during pregnancy and prior to conception
  - Paternal risk factors prior to conception
  - Included risk factors that would be captured in claims such as: preterm birth, chronic maternal health conditions prior to pregnancy or during pregnancy (e.g., asthma and depression), medication use, anesthesia use, infertility treatment, and early immunizations
- Estimated sample size of mother-child pairs and father-child pairs for each risk factor and comparison groups

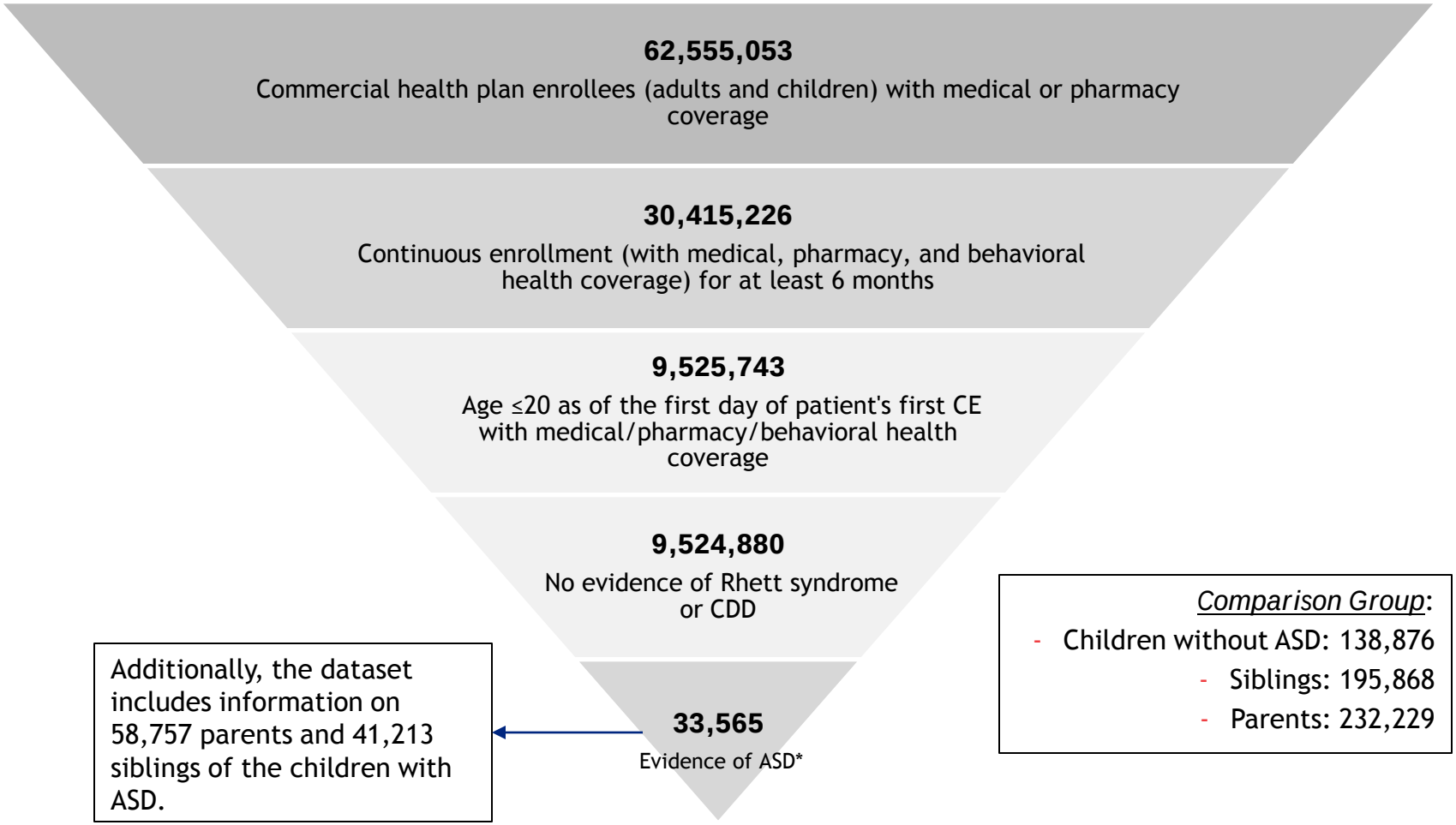
Strengths and Limitations

- Strengths
  - Large dataset that is generally representative of the US population
  - Constructed a cohort of children highly probable to have ASD, which is larger than many comparable studies on ASD
  - Data spans a ten-year period
  - Were able to link children with ASD to their family members and examine the impact of ASD on sibling and parental health
- Limitations
  - Administrative claims data are generated for payment purposes, so diagnoses that do not impact payment are likely under-reported (e.g. obesity)
  - Severity of ASD not well captured in data (e.g. Mental retardation and non-verbal status likely under-reported)
  - Surveillance bias may have impacted our results (though our analysis suggested it was not a significant factor)

Question and Answer Session

QUESTIONS?

Study collected information on a large sample of children with ASD



Additionally, the dataset includes information on 58,757 parents and 41,213 siblings of the children with ASD.

Comparison Group:
- Children without ASD: 138,876
- Siblings: 195,868
- Parents: 232,229

*presence of two or more claims with an ICD-9 for Asperger's, Autism, or PDD-NOS

Sample Sizes for Risk Factor Research

	ASD	Comparison
	N (%)	N (%)
Mothers identified via FAMID and appropriate age relative to child with ASD (or comparison child)	**31,329**	**119,143**
Mothers identified via validated methods (e.g., enrolled at birth of child between 2001 - 2009)	2,176 (6.9%)	10,703 (8.9%)
Fathers identified via FAMID and appropriate age relative to child with ASD (or comparison child)	**30,191**	**119,143**
Enrolled at conception (+/- 7 days)	1,513 (5.0%)	7,204 (6.0%)
Children	**33,565**	**138,876**
Enrolled birth to 24 months	1,767 (5.2%)	4,876 (3.5%)