

# Study of Health Outcomes in Children With Autism and Their Families

Client: National Institutes of Health, National Institute of Mental Health

## Project Overview

This 2-year study utilized de-identified health insurance claims data to describe the range of medical conditions experienced by children with autism spectrum disorders (ASD) and the health outcomes of the children and their families. The study addressed a significant gap in the empirical knowledge base about the trajectories of health outcomes and utilization of health care services among children with ASD, their siblings, and their parents.



Goals of the study included:

- Describe the baseline characteristics of children with ASD and their families and assess the accuracy of the ASD diagnoses within the study population.
- Examine the health outcomes of children with ASD and their families, including adverse medical outcomes and the progression of these outcomes over time, and compare these outcomes to those of demographically matched controls.
- Quantify the health care utilization of children with ASD and their families over time, including inpatient and outpatient health care and behavioral care, and compare utilization with controls.
- Investigate the potential value of administrative databases for future studies of risk factors associated with ASD.

Summary of Three Datasets Used for This Project

Data Set Attribute	Data Set		
	AHPMxRx	AHPMx	BPO
Annual lives	15M	9M	9M
Timeframe available	2001 - 2009	2001 - 2009	2004 - 2009
Positive enrollment	Y	Y	Y
Medical information	Y	Y	Y
Pharmacy information	Y	N	Y
Socio-demographics	Y	Y	N
Family linkage	Y	Y	N
Potential for chart access	Y	Y	N

As a subcontractor to The Lewin Group, Insight led the External Advisory Committee (EAC) in its efforts to provide guidance and consultation on the design and implementation of this study, and also provided subject matter expertise in the analysis of existing de-identified health claims datasets to compare health outcomes and utilization for children with ASD and their families with demographically matched controls. Results of the study provided new insights into the health care experience and health care needs of these children and their families by helping the National Institutes of Health (NIH) and clinicians to better understand the impact of ASD on the overall health of children, their siblings, and their parents, as well as how families with ASD navigate the health care system.

## Core Activities

Stakeholder Engagement and Coordination of Advisory Committees and Technical Expert Panels; Report Development and Presentation

## Products

This project produced 5 reports and 3 associated manuscripts.

